RELIGIOUS AND SPIRITUAL COPING METHODS

FOR HOSPICE VOLUNTEER

CAREGIVERS

THESIS

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By

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To my parents and family members, in gratitude for their
endless supply of support and encouragement

and

To the faculty and staff members at
Southwest Texas State University, in appreciation of their
guidance, humor and wisdom.

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TABLE OF CONTENTS

TABLE OF CONTENTS

LIST OF TABLES

viii

ABSTRACT

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Fifteen hospice volunteer caregivers were interviewed to better understand the stressors they experience and ways in which they cope with them. Three focus group interviews were conducted to investigate types of care, stresses experienced, ways of coping, rewards experienced, and the use of religion and spirituality in hospice caregiving. The three men and twelve women in this study used a variety of ways of coping and helping patients and families to cope through the stages of illness and dying. A few of the respondents reported that as they spent more time volunteering and gained experience, they felt more relaxed in dealing with difficult issues, such as family dynamics. Spirituality played a strong role for this sample of hospice volunteers in the coping process and in finding meaning in death through reappraisal. Spiritual growth and joy in listening to and sharing with patients were rewards reported by the volunteers. The findings of this study reveal the important role that hospice volunteers play in assisting patients to transition into the "dying role." The findings also expose a potential need for hospice agencies to provide continuing education and support systems in order to retain volunteers. Overall, the volunteers reported more rewards than costs associated with their unpaid work, and these rewards were often framed in spiritual terms.

CHAPTER I

INTRODUCTION

Hospice volunteers perform a special function as part of a support team in providing end-of-

life comfort and care for those who are aging or have terminal illnesses. Their function is special

in that part of their purpose is to provide comfort and companionship during the care recipient's

final months of life. They are an integral part of a team that provides differing types of support

for the care receiver and the primary caregiver. The role of hospice is to provide palliative care

for the terminally ill in their last six months of life and support for caregivers, including

bereavement support after the loss of their loved one. Palliative care involves comfort and

alleviation of pain rather than seeking to cure the patient. Kane and associates (2000) describe

palliative care in these terms:

> Palliative care involves a gradual transition from a posture of hope for a cure to a state in which
> patient and family embrace the possibility of death and hope for other things of importance to
> them, such as peace and understanding, control of pain, enriching relationships, a meaningful
> death, and divine concern with the fate of their loved ones. (p.168)

The purpose of this research was to examine how hospice volunteers cope with, and assist

others in coping with, the dying process. In particular, the religious and spiritual coping activities

of hospice volunteers was of interest in this study. Previous research indicates that hospice

workers generally tend to be a spiritually focused group of individuals (Millison and Dudley,

1990) Previous research also indicates that spirituality is frequently used as a way to cope with

illness and dying (Stuckey, 2001; Picot, et al., 1997, Pargament, 1990; Pargament, et al., 1990).

This research was intended in part to explore the stressors experienced by hospice volunteers and

1

how they cope with them. Why is it important to study coping? As Pargament (1990) aptly

phrases it, " ...the study of coping offers one potential bridge joining the gap between our

understanding of individual religiousness through the psychology of religion and of

religious systems through the sociology of religion" (p.213). It helps us to consider social-

contextual variables that aid in the process of coping and not merely focus on the individual as

separate from society.

In order to study the coping methods and experiences of hospice volunteers, I conducted focus

group interviews, in the Fall of 2002, with three separate groups of volunteers at three hospice

agencies in two Texas cities. The qualitative, exploratory nature of this research will

provide a further understanding of the struggles and victories of hospice volunteer caregivers.

This study examined the following research questions with regards to hospice volunteers:

In dealing with stressors, how often do they use religion and spirituality as part of the coping

process? What other types of coping do they use? Does religion or spirituality influence the way

in which they perceive the patient's dying? Does religion or spirituality influence both the

perceived rewards and the perceived costs of doing this line of work? In what ways, if any, do

their perspectives change as they cope with the dying, in a way that allows them to reframe their

definition of the situation? How do they assist others in coping with the dying process?

DEFINITION OF TERMS

Social scientists define the terms *stress* and *coping* in the following ways. The

meaning of these terms will be further delineated in later sections of this paper. Cockerham

(1998) defines *stress* as "a heightened mind-body reaction to stimuli inducing fear or anxiety in

the individual...(which) typically starts with a situation which people find threatening or

burdensome" (p.62). Pearlin and colleagues (1990) approach the study of caregiver stress from

the perspective of what they call the "stress process" (p.585). This focuses attention on the

changing nature of conditions and perceptions that lead to personal stress. Lazarus and Folkman

(1984) view stress in terms of the relationship between a person and their environment, "which takes into account characteristics of the person on the one hand, and the nature of the environmental event on the other" (p.21). The key concept used by Lazarus and Folkman in their evaluation of stress is *appraisal*, which has to do with how a person interprets the environmental event. Lazarus and Folkman (1984) indicate that psychological stress results when a person cognitively evaluates (appraises) a situation as "taxing or exceeding his or her resources and endangering his or her well-being" (p.21).

Coping involves how a person deals with this stress. Pargament (1990) defines coping as "a highly interactive process through which individuals try to understand and deal with significant personal or situational demands in their lives" (p.195). Pargament's (1990) framework for coping says that "coping is viewed as a continually changing process" (p.198), which involves a focus on problems, situations, or events of significance for a person. Pargament (1990:198) also says that coping involves both cognitive and behavioral effort (making the effort to both *understand* and *deal* with the event). Finally, he says that coping is concerned with processes of change and processes of interactions in dealing with the demands of life. The current study seeks to explore the stressors experienced by hospice volunteer caregivers and their methods of coping with them.

It is also important to differentiate between the terms *religion* and *spirituality*, as each may play a separate and unique role for individuals in the coping process. Stuckey defines *religion* as "a particular doctrinal framework that guides sacred beliefs and practices in ways that are sanctioned by a broader faith community" (2001:70). Religion provides structure to the way that people worship by providing guidelines, beliefs, and practices. "*Spirituality* refers to beliefs and practices that connect persons with sacred and meaningful entities beyond themselves" (Stuckey 2001:70). Millison and Dudley (1990) define *spirituality* as "pertaining to or consisting of spirit, soul, or incorporeal being, as distinguished from the physical being" (p.65). Spirituality involves the creation and sustenance of a personal relationship with a supreme being, as defined by the person's own belief system. The intent is to provide a sense of meaning and purpose to life.

Stuckey (2001) says "Although they are not mutually exclusive, religion emphasizes a communal type of worship and spirituality emphasizes a personal or meditative worship experience" (p.70). Because this is a qualitative study, the terms *religion* and *spirituality* have been left open for the respondents to define. However, the above explanation is provided to indicate the delineation of the terms in previous research of a more quantitative nature. The current research is intended to explore how the respondents use religion or spirituality, as they define it, as a means of coping in caregiving.

The next chapter will include a discussion of caregiver stressors, a multitude of coping methods used by caregivers, and social support and its influence on the coping process. The importance of combining science and spirituality, when desired by patients and their caregivers, in palliative care is also addressed. Finally, sociological theory, and the implications of death and dying for the understanding of human behavior will be addressed. Chapter Two will be followed by an in-depth discussion of the research methods, data, and findings. The concluding chapter will summarize the main findings, discuss strengths and weaknesses of the project, and describe implications for future research.

CHAPTER II

CAREGIVER STRESSORS, COPING METHODS, SOCIAL SUPPORT, AND SOCIOLOGICAL THEORY

There is a well-established area of sociological and social psychological research on caregiving, caregiving stressors and measures of stressors, coping methods for dealing with stressors, and social support of caregivers. The sections that follow will discuss previous research in each of these areas, with additional attention given to different types of caregivers for the dying, including family and paid caregivers, as well as hospice volunteer caregivers. Next, I discuss relevant sociological and social psychological theories that are relevant to explaining these caregiving processes.

One prominent conception of caregiver stress views it as resulting from a process that comprises a number of interrelated conditions, which include "the socioeconomic characteristics and resources of caregivers and the primary and secondary stressors to which they are exposed" (Pearlin, et al. 1990:583). Pearlin and his associates proceed to define primary stressors as the trials and problems associated directly with caregiving. Two categories are delineated for secondary stressors. These are strains associated with roles and activities outside of the caregiving role, and intrapsychic strains, which act to decrease self-concept or self-esteem. Caregiver stress, then, involves a process which involves the interaction of caregiver characteristics and resources with the stressors to which the person becomes exposed.

Pearlin and colleagues (1990:585) examine four domains in the stress process, which are: the background and context of stress; the stressors; the mediators of stress; and the outcomes or manifestations of stress. Background and context concern the key characteristics or ascribed statuses of the caregiver, such as age, gender, race, occupation, and level of income. These characteristics influence where people stand within a stratified social order, which offers unequal distributions of opportunities and rewards based on status. Aspects of the caregiving history, such as the relationship of the caregiver and care recipient, and duration of caregiving activity are an important part of caregiving background to consider as well (Pearlin, et al. 1990:586). The stressors and background factors will be discussed in detail here.

CAREGIVER STRESSORS

Different types of stressors have been delineated in the literature. As noted by Thoits (1995), stress literature has focused on three major forms of stressors, which are: life events, chronic strains, and daily hassles. *Life events* are acute changes requiring major readjustments within a relatively short period of time, such as the birth of a first child, or divorce. *Chronic strains* are defined as persistent or recurring demands, which require readjustments over prolonged periods of time, such as poverty, marital problems, or a disabling injury. *Hassles* (and uplifts) are mini-events requiring small behavioral readjustments during the course of the day. In the case of caregiving, all three forms of stressors can affect the caregiver, depending on their particular circumstances, and multiple stressors can occur together to create more impact.

Previous research demonstrates that a multitude of stresses are faced by caregivers for the dying. Much of the past research on caregiving focuses on primary family caregivers, but some research has been conducted on volunteers and paid caregivers as well. Stresses are defined in one study as "situations perceived and appraised by persons as personally relevant to their well-being, but also taxing or exceeding their resources" (Picot, et al. 1997:90). A large portion of this past research focuses on stressors and how caregivers cope with them. Types of stressors caregivers

face include stigmatization (Snyder, Omoto, and Crain, 1999), devaluation as unpaid workers (Olesen, 1989), emotional/psychological strains (Hull, 1990; Olesen, 1989; Picot, et al., 1997), financial strain (Picot, et al., 1997), guilt (Hull, 1990), and caregiving duration. Communication and decision-making problems can be an additional source of strain for caregivers (Hull, 1990; Kane, et al., 2000; McGrath, et al. 1999; Mezey, Miller, and Linton-Nelson, 1999). Volunteers, in particular, are likely to experience the stresses associated with stigmatization, devaluation, communication, and emotional/psychological strains. Additional stressors experienced by *family* caregivers include worsening patient symptoms, interacting with others, and concerns for self (Hull, 1990). These stressors are likely to affect *volunteer* caregivers as well. A discussion of background/contextual variables and various other potential sources of stress for caregivers follows.

Background/Contextual Variables

Several background/contextual variables correlate with caregiver stress. Pearlin (1989) discusses the various systems of stratification that cut across society, such as those based on social and economic class, education, race and ethnicity, gender, and age. Pearlin indicates that "to the extent these systems embody the unequal distribution of resources, opportunities, and self-regard, a low status within them may itself be a source of stressful life conditions" (p.92). For example, a person's race can influence the resources that are available to them, whether they be financial, emotional, or physical resources, to cope with stress. A person's demographic characteristics can also influence how they use resources and which ones they use. Caregiving duration is also considered a contextual variable and will be addressed in addition to the demographic variables noted. We will first examine age as an influencing variable.

Caregiver age. Much of the caregiving literature find that primary family caregivers frequently tend to be wives who are themselves aged (mid-fifties and older), or daughters of the care receivers, ranging in age from mid-forties to mid-sixties (Farran and Miller, 1997; Hull, 1990; Kinney and

Stephens, 1989; Kirschling, Tilden, and Butterfield,1990; MacDonald, 1998; Novak and Guest,

1989; Pearlin, et al., 1990; Picot, et al., 1997). One national survey indicates that 22 percent of

family caregivers are age 20 to 34 years, 39 percent are 35 to 49 years, 26 percent are 50 to 64

years, and 12 percent are 65 years and older (National Alliance for Caregiving and AARP, 1997).

These data indicate that more than one-third of family caregivers are aged 50 years or older.

Sometimes caregivers are caught between generations, taking care of their own children and their

aging parents at the same time. For example, the same national survey found that 41 percent of

family caregivers had kids at home and 59 percent had no kids at home. A substantial percent of

caregivers are responsible for caring for both children and aging parents. Caregiver age is an

important research consideration because caregivers are faced with potential health problems that

come with aging, which can produce additional stresses for them. The special needs of those caught

between generations is also important to consider, as they are often working caregivers who care

for children and aging parents at the same time.

Gender. Gender is a significant caregiver variable to consider, in addition to age. Primary

family caregivers and hospice volunteers most frequently are women. One national survey indicates

that 73 percent of family caregivers are female and 27 percent are male (National Alliance for

Caregiving and AARP, 1997). Field and Johnson (1993) mailed questionnaires to 406 current

volunteers and 46 former volunteers with a hospice organization in the United Kingdom, of which

the majority (88%) were female (p.1627). Even though most caregivers are women, studies have

compared men and women's experiences and strategies for dealing with stress. Pearlin (1989)

notes that gender can influence the types of stressors faced and how one copes with them. The

literature shows that there are more women than men caregivers. Olesen's (1989) non-empirical

article addresses gender implications in caregiving. For example, she suggests that men approach

caregiving instrumentally, while women are more expressive in caregiving. Instrumental activities

would be more task-oriented, while the expressive have more to do with emotions, managing

feelings and dealing with conflict. If women are more expressive in caregiving, this could potentially create more emotional strain with caregiving for women. Olesen also addresses the unequal access to resources for male and female caregivers, and the gendered aspects of the work of care, which also can be potential sources of stress. According to Olesen (1989), the role of women as caregivers constitutes an "issue within the sociological analysis of the division of labor in our society and in the relationship of gender stratification to that division of labor" (p.6). Accessibility to resources and differing role expectations for women are two important considerations in the area of stress research.

Race. In addition to gender, the race of the caregiver and the care receiver are significant influences to consider in the caregiving interaction. Blacks have been shown to experience and deal with stress differently than do whites. Farran and Miller (1997) found that black spouse caregivers report lower levels of emotional distress than do white spouse caregivers of people with dementia, and black caregivers are less likely to report depression and role strain. In exploring the positive side of caregiving, Picot and associates (1997) compared the perceived rewards of black and white caregivers. They examined the mediating factor of religiosity in influencing stress effects and perceived rewards for caregivers. Their findings indicated that black caregivers perceived more rewards than white caregivers and less educated caregivers perceived more rewards than more educated caregivers (p. 96). Picot and colleagues found that white caregivers had more education and higher incomes than did the black caregivers, and subsequently reported fewer perceived rewards, suggesting that whites perceived greater costs in relation to their careers and incomes. Black caregivers also scored significantly higher on prayer and comfort from religion than white caregivers (p.98). Tolliver's (2001) study of African American female caregivers of family members with HIV/AIDS suggests the importance of recognizing that these caregivers may experience discrimination and racism in accessing social services, which can create a higher level of burden and stress for them (p.147).

The above mentioned study (Tolliver 2001:153) also indicates that there are extreme economic burdens associated with HIV/AIDS caregiving, including the costs associated with missed time from work, and costs of care, medication and food supplements. Because blacks are disproportionately affected by the AIDS epidemic, Tolliver states that it is important to understand social inequalities based on race, and to be aware of specific caregiver needs associated with AIDS. Race, therefore, impacts the type of distress experienced, the way one copes with and perceives stress and rewards in providing care, and the resources one has available for coping.

Caregiving duration. Caregiving duration is another influential contextual variable examined by researchers, both for family and volunteer caregivers. In looking at caregiving duration, Kinney and Stephens (1989) found that caregivers who had been caring for dementia patients for a relatively longer period of time scored lower on the caregiving hassles scale used in that study (p.332). Kinney and Stephens suggested that the caregivers had become accustomed to a usual routine as they spent more time caregiving, and thus experienced fewer hassles. The study conducted by Picot and colleagues (1997) recorded caregiving duration "as the total months since the caregiver started providing a minimum of 5 hours of care per week to the care receiver" (p.93). When asked in a national survey of family caregivers how much longer they might be a caregiver, 64 percent of respondents reported less than five years, while 21 percent expected it to last between five to nine years, and ten percent expected a duration of ten years or more (National Alliance for Caregiving and AARP, 1997). The same survey asked what types of assistance these caregivers provide. Activities of daily living assistance, transportation, housework, meals, laundry, and buying groceries were the most frequently engaged in tasks, while legal, financial and healthcare tasks were common, but not as frequently engaged in. Toseland and McCallion (1997) indicate that it is important that caregiving research focus more on caregiver "career" variables, which they define as length of time spent providing care and type of care provided (e.g. for a chronic illness). They noted that these variables have received scant attention in caregiving literature.

Caregiving duration for *volunteers* is important to consider as well, for they too are susceptible to caregiver burnout (Field and Johnson, 1993). Social support can also influence duration of service for volunteers. It would be expected that more social support would decrease burnout and increase length of service. Interestingly, one study of AIDS volunteers found a *negative* social path from social support to duration of service, and indicated that those individuals who reported greater social support in their lives actually spent less time as AIDS volunteers (Omoto and Snyder, 1995). Omoto and Snyder examine motivations for volunteering, and explore egoistic versus altruistic motives (p.683). They believe that certain individuals who are low in social support may choose to volunteer and remain a volunteer for more self-oriented reasons, such as attempting to meet people and make friends. They suggest that those people who are already high in social support are "early casualties of the stress associated with AIDS volunteerism" (p.683) because they have become accustomed to having large and available social networks, which may dissipate as a result of the stigma attached to AIDS volunteerism. The psychic costs associated with being an AIDS volunteer is therefore stronger for them, and affects their duration of service.

Caregiving duration, and its complex interaction with social support, can be an important consideration in the study of caregiver stress and coping. Duration of caregiving, along with demographic variables, such as age, gender, and race can influence the caregiving experience in sometimes complex ways. Other types of stressor variables to consider are explored next.

Types of Stressors

Role strain. An important consideration in the analysis of caregiver stress concerns work and role strain. Role strain can take place when caregivers work at a paid job and also take care of a sick or dying person. Role strain occurs when a person is burdened with expectations (either by themselves or others) to perform numerous roles, and it becomes overwhelming because they have too much to do. Field and Johnson's (1993) study of hospice volunteers found that nearly a third of the volunteers were in full- or part-time paid work, while 40% were retired (p.1627). Balancing

paid work and unpaid work can be a challenge, especially for family caregivers who have less of a choice in the matter than do volunteers. As Olesen (1989) states, the caregivers become responsible for participating in defining health and illness in the family, and must prepare food, manage emotions, and take care of other daily needs, as well as frequently working in a paid job (p.5). They become involved in multiple responsibilities, which must be dealt with on a daily basis, usually over an extended period of time. In addition, they may be expected to take on various roles, such as employee, spouse, parent, and caregiver, and be forced to prioritize and sacrifice certain involvements in order to manage their time and cope with stress.

Stressors for hospice volunteers. A study of hospice volunteers in the United Kingdom explored the reasons why they chose to volunteer, and the stressors they experienced with volunteering (Field and Johnson, 1993). Field and Johnson's hypotheses were that patient contact would be a source of stress for volunteers, and that such stress might cause them to want to give up volunteer work. They did not find support for either prediction. Instead, Field and Johnson found that the volunteers reported that their commitment was affected by changes within the organization itself, as it grew and experienced turnover of paid staff members (p.1631).The researchers noted that a key element in the organizational changes is that they largely occurred without volunteer involvement or input. Patient contact was not found to be a stressor for this group of volunteers or a reason for quitting volunteering. Rather, Field and Johnson (1993) found evidence to indicate that organizational growth had more of a negative effect upon commitment, feelings of belonging, and motivation of some long-term volunteers (p.1632). Volunteers in the Field and Johnson study were primarily affluent women, who were not in paid employment, so most did not have the pressures of outside work. If these findings are generalizable to other hospice volunteers, it would appear that patient contact is not an important source of stress for hospice volunteers. However, this may not hold true, as different hospices may have differing types of volunteers, with differing background

variables and life experiences than the Field and Johnson group. The types of patients and the diseases they deal with can also impact the level of stress with which they must cope.

Stigmatization. Stigmatization is an important consideration for some caregivers, especially those who work with patients that have a stigmatized disease. Stigmatization results from being negatively labeled by society in some way. For example, in the case of caregiving, stigmatization by association can occur for caregivers of those who have HIV/AIDS. They are treated as though they have violated the norms of society and are sometimes held to be guilty merely by association. One study found that both volunteers and non-volunteers consider AIDS volunteerism to be more stigmatizing than other forms of volunteering (Snyder, et al. 1999:1175). Snyder and colleagues found that expectations of negative interaction with others due to stigmatization deters people from becoming involved as AIDS volunteers (p.1185). Moreover, the study found that for those who did proceed with becoming AIDS volunteers, greater perceived stigmatization among these volunteers was related to decreasing satisfaction and increasing burnout (p.1187). Buckingham and Meister (2001) analyzed experiences of parents who have children with AIDS. They discuss the parent's fears over disclosing the AIDS disease to their child, because of the desire to protect them both personally and socially . Buckingham and Meister (2001) also state that there is a strong "potential for social stigmatization and ostracism that can erupt among the child's community of friends" (p.463). Acknowledging AIDS brings the potential for conflicts and guilt as to how the child contracted AIDS, as well. Stigmatization can therefore lead to burnout, social isolation, conflicts, guilt, and other types of emotional difficulties, as well as problems with accessing needed resources. All of this can place a tremendous amount of strain on caregivers and those for whom they are caring.

Devaluation as unpaid workers. Being devalued for the work they do can also be a major source of strain for caregivers and can negatively impact their self-esteem, as well. Olesen (1989) studied the experiences of informal care providers. Olesen (1989) discusses specifically concerns

about women as informal caregivers, and the devaluation of their work, whether at home or in the workplace (p.5). If the value of their contributions to the production of health and well-being is not recognized, this can be an additional source of stress for them. They may feel that their work is not appreciated, but is expected of them. This devaluation of caregiver productivity also has implications for the division of labor at work and at home, which frequently is inequitable for women and can place an uneven load on them. For example, a female caregiver may still work a full-time job, but then be expected to be the primary caregiver of an elderly relative, despite other individuals being available and capable of doing the work of caregiving, as well. The role overload can create physical, as well as emotional strain for anyone placed in this position and not being valued for their contributions.

Emotional/psychological strains. Emotional and psychological strains experienced by family and volunteer caregivers are examined frequently in the caregiving literature. In a qualitative study of families that cared for their dying relative in an oncology hospice home care program, Hull (1990) found that the families identified three general sources of stress: patient symptoms; interactions with others (whether family, friends, or health care workers); and concerns for self (p.37). Patient symptoms included changes in mental status or physical deterioration in the care receiver. These physical or mental changes often bring about more dependence on the caregivers for the basic and personal activities of daily living (ADLs), which in turn can create more stress for the caregiver. In addition, the social interactions which can provide social support can also create conflicts and stresses for caregivers (France and Alpher, 1995; Hull, 1990; Field and Johnson, 1993; Kinney and Stephens, 1989; Kirschling, et al., 1990). As mentioned previously, Hull (1990) found concerns for self to be a source of stress for caregivers. Hull (1990) identified five areas that related to concerns for self (p.41). These five areas were: putting their lives on hold, personal health, lack of time for themselves, isolation from

family and friends, and feelings of guilt. For example, a caregiver may be expected to give up going back to school, or taking a much needed vacation. They may have less time for exercise, taking a relaxing bath, meditation, or other types of self-care. Less time for being with friends and other family members can also create feelings of isolation and depression. Guilt was related to inability to fulfill self-expectations about their actions and feelings toward their dying relatives (Hull 1990:45). Caregivers may feel that they should have or could have done something else to reduce the care receiver's pain or make them more comfortable, so they may experience guilt with regards to how they are performing their job. All of these emotional and psychological strains can build to create seemingly insurmountable stress for caregivers.

Summary of stressors. As can be seen from the research reviewed here, there are a host of stressors which caregivers face, involving both primary stressors, which relate directly to being a caregiver, and secondary stressors, which relate to the demand of roles outside of caregiving and intrapsychic strains related to self-concept. How does past research measure such stressors? This will be addressed next. It should be noted that some of the research also sought to measure caregiver rewards, and that will be addressed as well.

Measures of Caregiver Burden

Past research indicates the use of various quantitative and qualitative methods for measuring caregiver burden. The most prominent quantitative measures include the caregiver burden inventory and the caregiving hassles scale. Novak and Guest (1989:800) use the Caregiver Burden Inventory (CBI), which is designed to measure five different factors. Each factor includes five statements intended to measure that specific factor, which are rated by the caregiver in terms of impact on them. Factor one is called the "Time-Dependence Burden," which deals with the burden due to restrictions on the caregiver's time. Factor two is the "Developmental Burden," which refers to the caregiver's experience of missing out on their life and expectations of how their life should be. Factor three, "Physical Burden" measures feelings of chronic fatigue and damage to physical

health. Factor four, "Social Burden" addresses caregivers' feelings of role conflict. Factor five,

"Emotional Burden" uses items that describe the caregivers' negative feelings toward their care

receivers. The CBI is designed "to assess caregivers of cognitively impaired older people" (Novak

and Guest 1989:801). Their measure of caregiver burden shows that burden is a multi-dimensional

concept, which includes different levels or types of burden. Novak and Guest's CBI is a measure of

specific feelings of burden that have built over a period of time, rather than day-to-day hassles of

caregiving.

In order to measure day-to-day minor events that comprise the caregiving experience, Kinney

and Stephens (1989) utilized the Caregiving Hassles Scale. The authors point out the potential

threat of an accumulation of minor stressors over time, which are appraised by the individual as

threatening, and can result in negatively impacting their health (p.328). The hassles consist of

different specific care-recipient behaviors, care-recipient cognitive status, the behavior of friends

and family (social network hassles), and Activities of Daily Living (ADL) hassles, which include

such activities as bathing, lifting or transferring, and preparing meals for the care-recipient. The

participants in the Kinney and Stephens study completed a questionnaire to rate the degree of

hassle for these various activities. Picot and associates (1997) also examined care receiver deficits

in ADLs and care receiver deficits in instrumental activities of daily living (IADLs). Deficits in

ADLs dealt with "the care receiver's need for help with bathing, dressing, getting in and out of bed,

walking, toileting, and eating" while deficits in IADLs related to the care receiver needing

assistance with "meal preparation, shopping, light housework, heavy housework, and money

management" (Picot, et al. 1997:90). However, these same authors chose to measure caregiver

rewards with the 24-item Picot Caregiver Rewards Scale. This scale measured positive feelings and

outcomes associated with caregiving, which included items such as avoidance of nursing home

placement and the opportunity to repay the care receiver for a past debt. Some scales also explore

the physical and mental state of the care recipient and how that impacts upon the caregiver.

Perceived rewards of caregiving are an important area of examination too, since they also can provide a gauge of the health of the caregiver.

While the above studies used quantitative measures, such as burden and reward scales, Hull (1990) conducted a qualitative study using semi-structured interviewing to explore sources of stress for hospice caregiving families. She asked specific questions to explore the concerns related to caring for a dying relative, areas of the caregiver's life where they felt more need for support and understanding, the difficulties of caring for their relative at home, and the symptoms which they found most difficult to deal with (Hull 1990:34). A study conducted by Field and Johnson (1993) used both quantitative (closed choice questionnaire) and qualitative (interview) research to explore the stresses associated with being a hospice volunteer. The surveys included questions about reasons for becoming a volunteer, the demands of paid work, care of own families, and own illness, personal problems, or responsibilities (p.1627). The qualitative interviews were used to further probe any comments made at the end of the questionnaires. The Hull study and the Field and Johnson study are examples of a subjective approach to measuring caregiver burden and experiences, because it allows the respondents to direct (to some degree) the topic of concern or interest.

One qualitative study was aimed at understanding race- and gender-specific issues associated with caring for someone with HIV/AIDS. Tolliver's (2001) qualitative study examined the stressors and burdens experienced by African American female caregivers of family members living with HIV/AIDS. She utilized a semi-structured interview, intended to explore stressors related to disclosure issues (regarding the caregiver relative's HIV status) and the effect of HIV/AIDS on their lives. In order to take a non-threatening approach about an emotional topic, questions were not asked in a preset order, but followed the flow of the discussion (p.148). Tolliver explored the burdens associated with medical costs, attempts at obtaining social agency assistance, daily care, stigma, emotional trauma, and other issues specifically connected to dealing with AIDS.

Miscommunication can also be a source of difficulty and create an additional burden for caregivers. A study conducted by McGrath and others (1999) focuses on understanding communication stressors for palliative care nurses. This study used data analysis of written practice incidents that were part of a program called The Accelerated Professional Development Program (APD) offered to 181 registered nurses. This program was developed to help nurses in providing psychosocial care to terminally ill patients. The written practice incidents allowed them to identify situations of significance in their caregiving experience and to work at unresolved issues related to practice. To "measure" their experience, the researchers thematically analyzed the practice incidents to isolate and record significant topics. For example, they found that one substantial area of perceived burden for these nurses was in relation to talking to the patients about dying, specifically what to say when patients asked about it.

These studies show that there are diverse measurements, and multiple dimensions to consider in measuring and understanding caregiver stressors and burden. They also show that burden can be measured objectively (e.g. in terms of scales to measure a specific burden) or subjectively, through the relaying of experiences in caregiver interviews, to explore perceptions, fears and concerns. Clearly, even those scales directed at quantitatively measuring some type of burden are for the most part based on the subjective feelings of the caregiver. Caregivers invoke numerous methods in coping with stress, as well. The various coping methods are the next topic of discussion.

COPING METHODS

Chapter One states that coping involves a process in which individuals use both cognitive and behavioral efforts to deal with significant personal or situational demands in their lives (Pargament 1990). Individual coping activities and coping through the use of social supports will both be discussed in this chapter. Individual coping and coping through the use of social supports are not always readily distinguishable categories. For example, some social supports can be used by the individual in a way that helps them to individually reappraise a situation. There is an interplay

between the individual and the social system of which they are a part. Thoits (1995) states that

coping *resources* are social and personal characteristics, upon which individuals can draw and

apply to coping actions. These include social support (as a social resource), and sense of control

and self-esteem (as the two personal resources). Coping resources are brought into play by

individuals and/or groups of people, in the coping process, in order to deal with difficult life

situations.

Why do individuals attempt to cope? Lazarus and Folkman (1984) indicate that there are three

main functions or outcomes of coping, which are 1) functioning in work and social living, 2)

morale or life satisfaction, and 3) and somatic health (p.181). In other words, people evaluate and

cope with the stresses of living in order that they might experience a better quality of life and

maintain mental and physical health. Lazarus and Folkman (1984) view coping as an adaptive

resource which can sometimes help people gain strength and *grow* from stress (p.181). However,

the authors (Lazarus and Folkman, 1984) also point out that:

> ...coping should not be equated with mastery over the environment; many sources of
> stress cannot be mastered, and effective coping under these conditions is that which
> allows the person to tolerate, minimize, accept, or ignore what cannot be mastered (p.140).

In other words, efforts to manage stress do not always equate with mastery over stress or

environment. Lazarus and Folkman (1984) define coping in terms of "efforts to manage specific

external and/or internal demands that are appraised as taxing or exceeding the resources of the

person" (p.141). Their definition of coping as *efforts to manage* allows coping to be seen as a

process in which people *attempt* to deal with, but do not always master, stress.

Types of Coping Activities

What are the different types of coping used by caregivers who confront death and dying and in

dealing with daily demands of the caregiving role? The main types of coping activities reviewed in

the literature include problem-and emotion-focused coping, physical and behavioral coping,

relationship-focused coping, communication-building coping strategies, and attempts to control meaning of events.

Problem- and emotion-focused coping. Sometimes individuals deal with problems directly, and at other times, it is too much to deal with, so emotions are either denied or are raw and heavy. Thoits (1995) states there are problem-focused coping efforts and emotion-focused efforts (p.117). Problem-focused strategies are directed at dealing with the demands themselves. Emotion-focused strategies are aimed at dealing with the emotional reactions that frequently accompany these demands.

In a study of persons with AIDS, Weitz (1989) states that one type of problen-focused coping is vigilance, which involves knowledge-seeking, and acting on that knowledge, with the aim of reducing uncertainty about what can be expected in the future. This can help caregivers and patients to deal with potential symptoms of a disease or side-effects of treatments. Weitz indicates that avoidance is one more way of coping with uncertainty. She gives the example of persons with AIDS who attribute symptoms to a less serious ailment or avoid contact with physicians, in order to avoid knowing of their disease. Tolliver (2001) also indicates that denial is a major reaction for the caregivers in her study of black females caring for family members with AIDS. Denial may serve as a coping mechanism in that it allows the caregiver more time to accept and absorb the fact that their loved one is seriously ill. Anger at the situation was also frequently reported by AIDS caregivers (Tolliver, 2001). The expression of this anger may provide a form of emotional release for these individuals which may assist them in coping, at least in the short-term.

Physical/behavioral coping. Physical and behavorial activities are other ways to cope with illness and stress. Physical or behavioral ways of coping with illness and caregiving-related stress include eating balanced meals, use of vitamins, exercise, meditation, massage, seeking new treatments, and limiting the use of caffeine, tobacco, alcohol, and illegal drugs (MacDonald, 1998; McDonald and Fink, 1999; Weitz, 1989). McDonald and Fink (1999) sought to describe behaviors

that black and white caregivers report carrying out to maintain their own health. In a telephone survey, they asked the open-ended question "In general, what do you do to stay healthy?" (p.540). Their findings indicated that most behaviors addressed physical health, but caregivers also mentioned behaviors that contribute to mental and spiritual health. In addition to nutrition and exercise, other physical ways of coping included rest and relaxation, recreation, and socializing (p.543). Blacks were more than twice as likely as whites to mention following professional health advice, while whites were twice as likely to report staying busy or active, seeking help, and avoiding drugs as blacks (p.543). MacDonald (1998) found that massage as a respite intervention for hospice family caregivers was successful in reducing emotional stress, physical stress, physical pain, and sleep difficulties (p.44). These physical and behavioral activities are aimed at either preventing stress or dealing with it once it arises, and can be used promote physical, mental, and/or spiritual well-being.

Relationship-focused coping. Interactions with others is an important aspect of the caregiver role. Relationship-focused coping strategies were found throughout the literature (Baker, et al. 2000; Kramer, 1993; McGrath et al., 1999). Relationship-focused coping aims to maintain and regulate social relationships (Kramer, 1993). Kramer's (1993) study of 72 wife caregivers examines caregiver coping in terms of relationship-focused strategies, because caregiving is itself an inherently interpersonal or social act. Kramer further differentiates between negative and positive relationship-focused coping. Positive relationship-focused coping involves empathy, comforting and seeking of interpersonal solutions while negative focuses on such behaviors as blaming, withdrawal, or the silent treatment. Kramer's study further explores caregiver satisfaction and the type of coping used. Significant predictors of caregiver satisfaction included caregiver age, social resources, and problem- and positive relationship-focused strategies (Kramer 1993:391). Younger and better-educated caregivers reported using more problem-focused strategies, and younger caregivers reported greater caregiving satisfaction than did older caregivers (p.389).

Caregivers in poorer health and with fewer social resources use more emotion-focused strategies (p.389). In analyzing the relationship between coping strategies Kramer found that problem-focused coping was most strongly associated with positive relationship-focused coping, while emotion-focused coping was most strongly associated with negative relationship-focused coping. Those reporting more use of problem- and positive relationship-focused strategies reported higher satisfaction in their caregiver role. Finally, Kramer's study demonstrated that those providing care for shorter periods of time, and those trying to manage multiple problems, used more emotion-focused strategies. Emotion-focused strategies were associated with caregiving duration, while negative relationship-focused strategies were more strongly associated with interpersonal variables, such as social resources (p.391). Those with poor social resources tend to be more depressed, less satisfied with the caregiving role, and use more negative coping than do those with adequate social resources (p.392). Relationship-focused coping, then, can have either a positive or negative focus, and that can depend on such factors as caregiving duration, accessibility of social resources, and the degree and number of problems one is facing.

Communication-building strategies in coping. Communication is an important feature of all social relationships. Without proper communication, misunderstandings and mistakes occur, and people can become angry and frustrated with one another. Baker and others (2000) examine the importance of communication in relationships between professional caregivers and families coping with seriously ill hospitalized adults at the end of life. Their study compares hospice care and hospital care. Greater patient satisfaction has been reported with hospice, which focuses more on comfort and communication. The primary focus of their study was to measure family satisfaction when intervention occurs. Being able to participate in decision-making and communication with hospital staff was shown to improve satisfaction. When patient preferences for care were followed, family members also reported greater satisfaction. Communication and involvement in decision-

making and problem-solving, therefore appear to be important ways of helping family members and patients to cope with serious illness.

McGrath and colleagues (1999) analyzed communication stressors and coping among palliative care nurses ["palliative care" is care that is focused on pain management, symptom control and overall comfort for the dying patient]. Communication issues can be stressful for palliative care workers, especially due to issues of dying. The most frequently cited concern of the respondents in this study was talking to patients about dying. The authors of the study point out that good communication is important all along the way in palliative care because decision-making for patients and families include treatments to be accepted (or refused), pain and symptom management, whether to participate in clinical trials, and choosing where they want to die (p.29). Their study examines a professional development program for palliative care nurses that trains them in dealing with these issues.

These studies demonstrate that communication is especially important in palliative care, since a person's dying is an extremely trying event for all concerned. Communication aimed at assisting in the knowledge process and decision-making is a particularly potent coping mechanism. It empowers the care receiver and their families by eliminating or reducing some of the feelings of isolation, fear and doubt associated with illness and dying.

Finding or controlling meaning. Finding meaning or controlling meaning is a common coping method found in the literature (Birenbaum, 1990; Farran and Miller, 1997; Pearlin, et al., 1990). Birenbaum's (1990) study examines families coping with childhood cancer, and the relationship interactions they use to deal with it. She delineates two concepts (*encapsulation* and *at-risk strategies*) that she considers to be ways of coping. *Encapsulation* involves normalizing the experience and seeking to control the meaning of the illness. *At-risk strategies* include complying with treatment and protecting the child. Birenbaum (1990) states that families construct an illness perspective that allows them to regulate and control emotions, in coping with cancer (p.19).

Encapsulation includes trying to normalize the child's life as much as possible (depending on the intrusiveness of symptoms and medical regime, and other factors of impact), such as keeping them in school or disciplining the child when they misbehave. Encapsulation also involves attempts (both cognitive and behavioral) at controlling the meaning of the experience. Examples of cognitions that control the meaning of experience might include an optimistic viewpoint, endowing the illness with meaning, and affirming life, while behaviors would include living day to day, open communication, and treating the child as normal (p.20). At-risk strategies include compliance with treatment and protecting the child, which includes monitoring signs, symptoms, and infection prevention. Birenbaum (1990) also states that parents can play a major role in assisting with the coping process for children by ascribing meaning to the illness in such a way as to "at least neutralize energy depleting aspects of this illness" (p.23).

Building on the work of Pearlin and colleagues (1990), Farran and Miller (1997) examine ways of finding meaning for black and white caregivers. Finding meaning and management of meaning are similar in that they involve a caregiver's attempts at understanding their family member's illness from a broader perspective. Management of meaning primarily involves a *cognitive* process, such as decreasing one's expectations or using positive comparisons (Farran and Miller, 1997). Finding meaning is cognitive but also transformative in nature. People transform how they think and feel about a situation, to create something new. Farran and Miller conducted in-home structured interviews with a sample of male and female spouse caregivers of persons over the age of 60 with a diagnosis of some form of dementia and co-residence with the caregiver. Their measures included subscales for *provisional* meaning and for *ultimate* meaning. The *provisional* meaning subscale focuses on caregiver enjoyment of what they still have in terms of a relationship with their spouse, and the *ultimate* meaning subscale focuses on identification with a spiritual or religious belief system (Farran and Miller 1997:320). Their Global Role Strain scale is a summary measure of emotional distress. Blacks in their study reported lower levels of income than whites,

and more blacks than whites were Protestants. They found, "Whites reported higher levels of distress with behavior problems and physical health, significantly lower levels of both provisional and ultimate meaning, and significantly higher levels of both depression and global role strain" (p.321). As hypothesized, they found that higher levels of provisional meaning were associated with lower levels of global role strain. They noted that provisional meaning appeared to have a more immediate and direct effect on caregiver distress, and may act more as a coping strategy than ultimate meaning. Farran and Miller (1997) suggest that ultimate meaning (related to religion and spirituality) may function more generally in shaping caregiver values and cognitive appraisal and reappraisal. They suggest that the more favorable response to caregiving by blacks may relate to culturally learned methods of adapting to and surviving difficult situations by making positive appraisals. Finding meaning or controlling meaning helps the individual in the coping process by allowing them to cognitively make some sort of sense out of their experience. It helps them in their attempts at understanding what is happening in their lives.

As demonstrated in the literature, coping includes both cognitive and behavioral processes, and can be problem-focused, emotion-focused, or relationship-focused. Shaping or reconstructing meaning can help one to cope by seeing the situation in a new way.

The Importance of Appraisal of the Situation

Studies demonstrate that stressors and methods of coping can directly and indirectly affect the caregivers' negative or positive appraisal of a situation and how they come to terms with it. Appraisal has to do with interpretation of events and circumstances. Pargament (1990) indicates that the *subjective* meaning of an event or situation to the individual is a critical part of their appraisal of and response to it (p.198). Braithwaite's (1992) study of caregiving burden recognizes burden to be a subjective phenomenon. What one caregiver may consider difficult may *not* be considered difficult by another caregiver. Subjective burden is more personal while objective is usually related to some type of measure, such as daily hours spent performing caregiving activities.

Braithwaite indicates that there are unclear boundaries between objective and subjective burden, which can limit its usefulness as a scientific construct. Lazarus and Folkman (1984) say that a concept of appraisal is necessary because although certain environmental demands and pressures produce stress in many people, the degree and type of reaction to stress can always differ both among individuals and among groups of people (p.22). Differences in sensitivity and vulnerability to events, as well as differences in interpretation and reaction must be considered. Environmental situations that superficially appear the same, may be quite different or have subtle differences which contribute to differing interpretations and reactions. It is important to consider appraisal in coping because "Appraisal processes.... mediate reactions and are essential for adequate psychological understanding" (Lazarus and Folkman 1984:24). From a sociological standpoint, appraisal helps us to view and understand the complex interaction between persons or groups of persons and their environment, and how people apply meanings to situations based on their perceptions and belief systems.

Lazarus and Folkman (1984) indicate that there are *person* factors and *situation* factors, which both influence appraisal. *Person* factors are commitments and beliefs. Commitments are those things pertinent to a specific transaction between person and environment, whether that be commitment to an ideal, an objective, or a relationship. Beliefs are cognitive configurations which are "personally formed or culturally shared....preexisting notions about reality which serve as a perceptual lens" (Lazarus and Folkman 1984:63). These include a person's beliefs about personal control, which is particularly relevant in terms of coping with illness and dying. *Situation* factors include novelty, predictability, event uncertainty, temporal factors, and ambiguity. The situation factor of novelty refers to newness of a situation – one that has not been experienced before. The situation factor of predictability refers to some type of forewarning that something painful or harmful is about to happen and predicts that those who have forewarning can prepare their response to a situation, and therefore, potentially experience less stress. Event uncertainty relates to

the notion of probability. In the case of illness, this might include the probability of a person having a recurring tumor. The effect of not knowing what might happen can be heightened anxiety, constant appraisal and reappraisal, conflicting thoughts and behaviors, and feelings of helplessness and confusion. Temporal factors, such as anticipation time, can also influence appraisal. For example, if someone loses a spouse suddenly in a car accident, they have not had the same prolonged period of time for reflection, grief, and coping as someone who has experienced a prolonged illness and death of a spouse. Caregiving duration is one temporal factor considered frequently in the literature on caregiving. If one has spent a longer amount of time in caregiving, they may either be experiencing more burnout, or they have learned how to deal with day-to-day issues in caregiving. In short, person factors and situation factors are both critical in understanding how the individual interprets their experiences. One's personal beliefs about illness, the type of illness, and the length of illness, for example, will affect how they perceive the situation.

Ambiguity is one final situational factor influencing appraisal, according to Lazarus and Folkman (1984). Ambiguity relates to a person's appraisal based on the information they have available, which is sometimes insufficient or unclear. In other words, the environment may be giving them mixed messages about what to expect, and therefore, creates an ambiguous situation. However, even when the environment is uncertain, a person can have confidence about what to do and act on it, refusing to allow themselves to be confused by the situation. All of these factors can influence appraisal and are important to consider in the study of stress and coping. These personal and environmental factors are interdependent and operate together to influence appraisal in the stress and coping process.

Religion and Spirituality in Coping

Religious or spiritual beliefs and practices often play a role in coping with and reframing a person's perception of a situation (Millison and Dudley, 1990; Pargament, 1990; Pargament, et al., 1990; Picot, et al., 1999; Stuckey, 2001; Weitz 1989). Stuckey (2001) employs the Reconciled

Life Perspective (RLP), which "refers to the extent to which individuals have reconciled their spiritual and religious beliefs and practices with adverse events in their lives" (p.70). Stuckey proposes that persons having a strong RLP are able to more effectively adapt to situations. Stuckey's (2001) findings indicate that having a RLP enables one "to transcend the immediacy of stressful life events while maintaining a connection to religious or spiritual sources of support, thereby increasing the likelihood of improved overall well-being" (p.83). Weitz (1989) found that developing positive explanations for an illness (i.e. attributing it as a gift from God to help build religious faith) or maintaining a positive overall attitude is one way of cognitively coping. Weitz (1989) also points to reliance primarily on prayer as a way of coping, by a few AIDS patients in her study (p.251).

Pargament and his associates (1990:813) found that religious involvement in coping with significant negative life events is commonplace rather than unusual. The study discusses religious and non-religious coping activities, and the additive nature of religious coping activities. They argue for the importance of *integrating* religious coping into the literature but also indicate the importance of not drawing too sharp a distinction between religious and non-religious coping, as the activities involved sometimes overlap (p.818). For example, people can cognitively reappraise a situation without necessarily bringing religion into the context of that reappraisal.

Pargament (1990) states that religion is a single component of the coping process, and that other practices, beliefs, and resources can be used in coping, as well (p.210). The use of religion or spirituality as a coping mechanism depends upon a person's commitment to their beliefs, the context or seriousness of a situation, and the type of life event (Spilka, Shaver, and Kirkpatrick, 1985). As an example, significant life events such as a wedding, a birth, or a death, are likely to incur the use of religious rituals in coping with or celebrating the event. Because dying is a significant life event, religion and spirituality are more likely to come in to call.

What types of coping activities are considered religious or spiritual in nature? Exploring

spiritual concerns, praying, or talking about God with patients were indicated as frequent

behaviors in one study (Millison and Dudley, 1990). Prayer is emphasized as an important theme

again in Stuckey's (2001) research, as well as turning to a church or synagogue for support,

seeking spiritual growth through the experience, or attempting to transcend loss to find meaning.

A comprehensive study of religious coping efforts asked respondents to reply to Likert scale items

to indicate the degree to which certain items were involved in coping (Pargament, et al., 1990).

They categorized several types of coping. Spiritually based coping was most often reported. This

consisted of emphasizing one's "personal loving relationship with God" (p.803) through emotional

self-assurances that God is loving and trustworthy, positively framing problems, accepting limits of

ability to control, and asking for guidance in problem-solving. An additional way to cope involved

performing "good deeds" in an effort to take the focus away from the negative event and instead

place the focus on living a more religious life (Pargament, et al., 1990). These "good deeds"

included attending religious groups or services, providing help to other church members, and living

a less sinful and more loving life. Pargament and colleagues found that seeking religious support

from clergy or other church members was an additional coping mechanism. Spilka and colleagues

(1985) indicate that an additional aspect of appraisal in coping involves attributions of

responsibility or control, such as attributing a difficult or painful situation to the will of a divine

being. This may, in effect, reduce the worry or self-blame experienced by individuals, and enhance

their well-being, by placing the responsibility and control in the hands of the Divine. Pargament

and associates found that more negative ways of coping included expressing discontent or anger

with God, pleading (such as asking God why it happened), or religious avoidance (focusing on the

world-to-come rather than the problems of this world). Religion, then, can play both a positive and

a negative role in the appraisal process.

One's experience with religious teachings or communities can influence how they perceive support, or lack thereof, from religion. Jenkins (1995) reported ambivalent ties to religion for those with HIV/AIDS. He states that those with HIV or AIDS can experience intolerance and stigmatization through some religious teachings and communities, while other religious communities can be a source of support, such as provision of HIV-related services. Jenkins had 422 HIV-seropositive military personnel complete self-administered questionnaires. In this sample, African Americans more frequently endorsed religious coping activities than did Caucasians (Jenkins 1995:137). Persons with AIDS, in this study, tended to adopt "new age" or other spiritual paths (for example, meditation, yoga, or visualization) in dealing with their dying, due to their ambivalence about organized religion. The study found that 53.6% had a personal sense of spiritual beliefs not really related to a formal church or organized religion (p.134). Moreover, membership in a specific denomination was less common, while endorsement of spiritual, nondenominational beliefs appeared more frequently (p.135). Those who were more "spiritually inclined emphasized proactive, transactional (with God), self-affirming, and self-regulatory religious activities"…while "those who identified with organized religion more often used their faith and place of worship as a source of support" (p.137). Those more oriented towards organized religion tended toward the belief that good deeds would be repaid (p.137). Jenkins noted that the use of religion may vary depending on the type of problem, and may only play a minor role for Caucasian males in coping with AIDS. He also states that religion may have more value and appeal in interventions that target coping and quality of life in women and African Americans. Past and current experiences with religion, and the type of illness being faced, therefore, are important factors influencing the use of religion in coping. Spiritual, rather than religious, coping may be more common among those who have had negative experiences with organized religion.

In conclusion, various types of coping efforts are used to reappraise, or sometimes avoid dealing with, life events or situations. The importance of social support and interventions for caregivers is addressed next.

SOCIAL SUPPORT AND INTERVENTIONS

Social ties and/or the perception of social support, including that through religious or spiritual resources, have been extensively researched in the caregiving literature. Social ties, including those associated with religious or spiritual support, are shown to directly improve mental health outcomes and mediate the impact of stress on such outcomes. Religion and spirituality may be especially relevant in cognitive appraisal of stressors and in dealing with emotions associated with those stressors. Hospice or palliative care provides one form of assistance in cognitive reappraisal of the dying process. A brief summary of social support and interventions for caregivers will be addressed here. In the literature on social support for caregivers, the use of religious and spiritual means for providing support is common.

Types of Social Support and Interventions

One definition given for social support is "interpersonal transactions that include one or more of the following key elements: affect, affirmation, and aid" (Antonucci, Sherman, and Vandewater 1997:1). In other words, social support involves interactions related to providing emotional, spiritual, or physical types of support. Kirschling and colleagues (1990) state that the types of social support include emotional support, appraisal support, informational support, and instrumental support. Individual, family, and group social support and interventions will be explored here.

Massage as respite. MacDonald's (1998) study discusses massage as a respite intervention for caregivers. She argues for the importance of direct support for the family caregiver in addition to the direct care provided to patients by hospice agencies. The caregivers in this study were given a series of massages on a weekly or biweekly basis, either in their homes or at the therapist's office.

These caregivers rated four items either on stress scales or in terms of specific symptoms, before their first massage and then again after receiving their last massage. The findings indicated that the massages significantly reduced reported stress and symptomatic problems on all four items: emotional stress, physical stress, physical pain, and sleep difficulties. MacDonald (1998) argues that massage can provide physical, emotional, and spiritual nourishment to caregivers.

Support group assistance. Besides individual interventions, such as massage therapy, there are group interventions, such as support groups aimed at assisting people to cope. Support groups can provide a variety of support, including emotional, informational, spiritual, and appraisal assistance. Bereavement assistance is available, through groups that provide grief support. Support may assist caregivers in finding the proper way to cope with difficult situations, in a more proactive and less reactive manner.

Lack of support or lack of awareness of support can lead to more fearful ways of coping. For example, those caregivers who do not feel supported in coping with caregiving stresses may tend to turn to the health care system more frequently when they aren't given the tools to deal with a sick or dying person. Peak and Toseland (1995) evaluated the impact of a spouse-caregiver support group on care recipient health care costs. The data indicated that those caregivers assigned to the control group (usual care with *no* support group intervention) had significantly higher health care costs for the care recipient than did those who were supported (p.438). The caregivers in the control group were perhaps not as secure about dealing with health problems, which suggests that lack of support can lead to higher reliance on the health care system and higher health care costs and in turn creates more stress for the caregiver. Peak and Toseland (1995) examine the economic impact, as well as changes in perceived burden for caregivers of elderly veterans who received support group assistance compared with those who did not. This study showed a positive impact, in several ways, for those who received assistance through the Caregiver Support Project (CSP). The primary focus of the study was to examine the impact, on the emotional and social well-being

of the caregivers, of attending regular support groups over the period of a year. The social worker

that led the project support groups provided health education and assistance in problem-solving

methods for more appropriate use of health services by caregivers. Mutual support and stress

reduction were also emphasized. The benefits of inclusion in the group included lower health care

costs, changes in appraisal (those in the control group perceived greater health declines in the care

recipient than did those in the support group), and fewer and shorter inpatient stays for care

recipients. This study shows the importance of social context and support in creating changed

perceptions, and reduced health care costs, for caregivers.

In his examination of social support in coping with stress, Maton (1989a) compares different

community settings as buffers of life stress. Maton examines the results of earlier studies

conducted by himself and his colleagues. Two of those studies related to bereavement stress and

community support. He examined the impact of bereavement support groups and senior centers on

the stress experiences of the respective members of each. The mutual help groups were shown to

play a stress-buffering role through friendships, mutual sharing, coping, grief, and companionship

opportunities. Maton did not find that the senior centers served this same role. A stress-buffering

relationship between setting support and well-being was not found at the senior centers, perhaps

because the organizational nature of these facilities tends to be more focused on leisure and general

service programs (Maton 1989a:228). Mutual help groups are shown to assist with grieving,

coping, and providing opportunities to connect with others.

Hospice support. Hospice provides support specifically for those who have a life-threatening or

terminal illness, usually with a prognosis of death in six months or less. The patient and family,

together, are considered the unit of care. Hospice care focuses on pain and symptom management,

and on psychosocial or spiritual support. Hospice provides a social context within which the

patient and family come to terms with illness and dying. It does so by bringing in a community or

team of hospice workers, usually into the patient's home, to assist and support the family and

patient. The team includes paid caregivers, a chaplain, a social worker, and hospice volunteers. Hospice care also includes bereavement support, for up to one year after the care receiver's death, for the caregivers. One study which reflects the importance of this type of social context in creating changed attitudes, explored the psychological impact of hospice on attitudes towards funerals and the post-death adjustment of bereaved individuals (Ragow-O'Brien, Hayslip Jr., and Guarnaccia, 2000). The sample consisted of individuals who had experienced the death of a family member or friend from a terminal illness. Fifty-seven of the participants used hospice care, while sixty-six used conventional care. The findings indicate that individuals who used hospice care reported more overall positive well-being and reported the funeral to be more meaningful than individuals utilizing more traditional types of care. Those who had used hospice care also reported participating more fully in the various rituals of the funeral, which may be useful in helping them to grieve and "deal more actively with the reality of the loss and move toward the acceptance of the death" (Ragow-O'Brien, et al. 2000:302).

Support for AIDS caregivers. AIDS is a particularly difficult illness to deal with because of the stigma attached to it, which often creates a barrier for receiving social support. Tolliver (2001) indicates that the African American female HIV/AIDS caregivers in her study indicated a need for both formal and informal support. The women in this study indicated turning to many different social agencies for support, including large hospitals, multiple doctors, counseling centers, and AIDS service agencies with either primarily white clientele or primarily black clientele. The respondents indicated feeling more comfortable seeking help from agencies with both African American clients and providers. However, Tolliver (2001) argues that the stigma associated with HIV/AIDS often prevents them from seeking help (p.147). Some of the women's recommendations were that social service agencies and medical institutions be more aware of the economic burden of AIDS caregiving. They also recommended better accommodation of caregiver work schedules, assistance with transportation (such as tokens for public transport to clinics), and prescribing less

expensive medications and food supplements. Tolliver also discusses the unique difficulties for African American females that result from racism and discrimination in accessing social services. The respondents indicated that they also frequently relied on religion or spirituality in coping and in attempting to understand why this was happening to their family, and they cited the need for emotional support to deal with the presence of HIV/AIDS in their families.

Spiritual and emotional support. The importance of spiritual and emotional support is well documented in the caregiving literature. Kane and colleagues (2000) analyze palliative and supportive care for children with terminal illnesses and their families. This study also refers to the need for emotional support for caregivers and patients. A comprehensive model of care, according to them, requires first that the physician in charge be understanding of the experience of suffering created by a serious illness, and secondly requires an integration of all services into the continuum of care. This comprehensive model involves care of the body, mind, and spirit and "facilitates a formal evaluation of the impact of emotional health and spirituality on disease and medical outcomes" (Kane, et al. 2000:167). Support includes the physician's understanding of family dynamics and the coping mechanisms of individual family members, and allowance for shared decision-making. Kane and colleagues (2000) conclude by discussing the need for humans to form community and have a sense of belonging, which can be facilitated by support group interventions.

Maton (1989b) explores the stress-buffering role of *spiritual support*, which he defines as "the perceived, personally supportive components of an individual's relationship with God" (p.310). Spiritual support for this study was construed as a "perceived social-environmental resource, rather than as a form of coping *per se*" (Maton 1989b:320). He analyzes two diverse samples. One of them consists of recently bereaved parents ("high life-stress" group) and less recently bereaved parents ("low life-stress" group). The second sample consists of first-semester college freshmen (also categorized into high and low stress groups). For the college students, those considered to have high stress had experienced three or more significant life events in the past six months.

Maton's findings indicate that spiritual support is inversely related to depression and positively related to self-esteem for high life-stress (recently bereaved) parents. Spiritual support was also positively related to personal-emotional adjustment to college for high life-stress first-semester college freshmen. Spiritual support was not significantly related to well-being for the low life-stress subsamples.

Chandler's (1999) article states that "spirituality has come to the forefront of public consciousness" and what was "once the prerogative of chaplains and clergy" (p.63) has now become a common concern. She emphasizes support in terms of hospice care and the nurturing of the search for spirituality, as distinct from organized religion, and addresses the use of sensory spirituality as a way to restructure what we see. The spiritual nurturance process consists of creating a "sacred space for patients" (p.71) to invite them to share their stories and their burdens. Chandler states spirituality provides holistic care that allows expression of feelings through art, music, and words as symbols to reinforce feelings. This type of support allows the patient to deal with grief and transition through encountering denial, anger, chaos, depression, and the other attendant elements associated with dying. In this way, dying can become a healing experience for both patients and their loved ones.

The Importance of Social Support

Why is social support for caregivers important? Some of the literature argues for social support in terms of equity and social justice, and not merely in terms of support in coping with stress. Pruchno (1990) investigated patterns of task assistance and social support for primary caregivers to spouses suffering from Alzheimer's disease. Her findings indicate that spouses report that they provide the bulk of assistance to their impaired partners, and report receiving minimal help from other people, including children who live locally. Sons were found to be particularly less available than daughters in providing assistance. Pruchno (1990) indicates that the heavy burden placed on the primary caregiver has important implications for service providers that work with caregivers,

which might include efforts to mobilize additional familial support, and taking into consideration the caregiver's particular needs. In their study, Antonucci and associates (1997) argue that not all social support interactions are positive. Some can be negative or conflictual. Thus, family members or others that may be considered sources of support, can also be sources of stress and conflict. This is important for service agencies to consider, as well, when addressing the needs of caregivers.

Braithwaite (1992) makes the argument for social support for caregivers based not on the notion of distress itself, but based on the need for social justice. She indicates that it is important to focus on the social system within which caregiving demands are embedded. In other words, burden should be tied to the conditions of living, and not just to the caregiver as a separate entity. Braithwaite (1992) states caregiver burden ties directly into theories of welfare rights and community care (p.17). A growing proportion of the population in the United States is elderly, and institutional choices will need to increase as the aged population increases. Braithwaite (1992) addresses the need for provision of institutional assistance to the traditional nuclear family, as they cannot deal with such issues as work commitments (inside or outside the home) and relationship challenges without outside support and assistance. As she points out, "women are particularly at risk, not only because they are more likely to become caregivers but because they are being denied the opportunity to be something other than a caregiver" (p.19). If aged care policies don't provide viable options, women are unable to pursue careers and economic independence and are often forced into inequitable situations without assistance. Caregiving burden must move beyond an individualistic phenomenon and become more of a social phenomenon, according to Braithwaite.

Overall, the caregiving literature suggests that identification of those caregivers at highest risk for experiencing stress will allow for interventions and social supports that are customized for their particular needs. Each caregiver's experience is unique and social support must be tailored to suit their desires and needs. Some individuals may request spiritual support, while others may need more physical assistance in dealing with issues of daily care. Some may require individual

interventions, while others may require family or group interventions. Consideration of cultural differences, such as racial and ethnic differences, should be considered in the delivery of care and interventions, as well. Hospice agencies, as well as other healthcare institutions, should be attentive to the changing needs of the caregiver and be there to assist them when they can. Hospice volunteer caregivers can provide insights into the special needs of caregiving families, because they interact with caregivers and care recipients on a fairly regular basis.

SOCIOLOGICAL THEORY

This section will address the primary sociological and social psychological theories that have been used to explain various caregiving issues. I will discuss the following perspectives: functionalism, social exchange theory, feminist perspectives, phenomenology, symbolic interactionism, dramaturgy, and attribution theory. These theories will be applied to caregiving, volunteering, and coping, as appropriate. Each of these theories has a place in explaining and understanding the use of religion and spirituality in the coping process, as well as in understanding individual motives for volunteering and coping behaviors. In particular, symbolic interactionism, dramaturgy, and functionalism help to explain the transition, provided through hospice, from the "sick role" into the "dying role."

Functionalism

The early French sociologist, Emile Durkheim, viewed society as an organism, composed of different parts, that function together to compose a whole. He stated that when society is strongly integrated, it holds individuals under its control. Durkheim (1951) argued that religion serves both a social and mental health function, in that it creates unity and commonality among individuals, i.e. social integration. Contemporary functionalists Ferraro and Koch (1994) argue that religion can serve as a gateway to supportive relationships (either with other individuals, or with a deity in some cases), which serve the function of social integration. They indicate that religion can act as a coping resource when people face structural and/or health disadvantages. Ferraro and Koch's

(1994) religious consolation (or comfort) hypothesis predicted that, faced with poor health or other forms of adversity, blacks would be more likely than whites to use religion for consolation and comfort. This hypothesis was supported by their research.

Coping serves various psychological and social functions in that it is directed towards keeping the individual healthy and functional within society by creating problem resolution, meaning, control, self-esteem, hope, intimacy, identity, and comfort (Pargament, 1990). Pargament states that these functions are multi-level constructs, because they are determined by the needs of the individual, as well as by the situational context and the response of the individual and/or their social system to life events and personal needs (p.201). Coping also serves the function of establishing stronger relationships (Kramer, 1993). Pargament (1990) states that religious functions of coping are to manifest spiritual growth or greater closeness to God. On the other hand, he notes that religion can act as a constraint to coping, because religions have "different types of congregations with differing theologies...various religious beliefs, practices, and orientations...which selectively encourage and discourage particular kinds of coping" (p.203). The type of religious system that an individual belongs to, and the degree to which they turn to it for support, will influence the degree of perceived support they experience.

Social facts, the "sick role" and the "dying role." Durkheim (1951) indicated that certain "social facts" (or external constraints) act upon the individual and influence them in their thoughts and actions, by establishing norms for behavior. These external constraints influence individuals in deciding what *roles* to take on and how to perform them. Different types of roles have differing expectations associated with them. Much of the literature in medical sociology has focused on the notion of the "*sick role*," developed by structural functionalist Talcott Parsons (1979). Parsons uses this label to describe someone who is unable to function normally in society due to some form of illness or impairment. The basic assumptions of the "sick role" are that the individual is experiencing a temporary state of illness, that they are not responsible for the condition, that they

are excused from normal roles and tasks, and they should seek competent help to try to get well.

Parker-Oliver (2000) builds on these ideas, and states the "sick role" is dysfunctional in the case of

those who are dying. She offers a new conceptualization, which she terms the "*dying role*," that

she deems a more appropriate role for those who are terminally ill. The "dying role" has different

expectations, according to Parker-Oliver. First, with some diseases, some individuals may be seen

as responsible for their condition. She gives AIDS as an example. Secondly the "dying role" is not

seen as temporary because the person is not expected to recover. Third, their former role (for

example, as an employee) is eliminated rather than being excused. In other words, they are not

expected to return to their former roles. Lastly, she proposes that the person is expected to seek

help and cooperate, but competent help and/or treatment for recovery may not be possible, and this

comes to be accepted in the "dying role." Parker-Oliver states that hospice plays the function of

assisting individuals in their care to make the transition from the "sick role" to the "dying role"

when it is realized they are not going to recover. The type of medical care and attention applied to

individuals in the dying role differs markedly from that provided to those who are in the sick role.

Hospice focuses on controlling pain and managing symptoms, to make the patient as comfortable

as possible, with the goal of enhancing quality of life, not prolonging life. The function of hospice

is to "help individuals renegotiate meaning and purpose by redefining their lives, not in terms of

being 'sick,' but in terms of living until they die" (Parker-Oliver 2000:500).

Social Exchange Theory

Social exchange theory holds that humans act so as to maximize rewards and minimize costs in

getting their needs satisfied. This theory is based on the work of George C. Homans (1958), who

states that "social behavior is an exchange of goods, material goods, but also non-material ones,

such as the symbols of approval or prestige" (p.238). Examples of non-material rewards could

include gratification, status, or social approval. Exchange theory challenges the notion in

functionalist thought that value and norms are the primary explanation for social behavior, arguing

instead that humans are motivated by a drive for maximum profit in social exchange. Several

studies have integrated this theory into their work (e.g. Kirschling, et al., 1990; Picot, et al., 1990;

Wilson, 2000). Kirschling and colleagues (1990) indicate that "human relationships involve

reciprocated exchange of valued commodities, the pursuit of which produces costs and conflicts"

(p.80). They note that social relationships are sources of both support and conflict. Their findings

in regards to hospice family caregivers indicated that they reported very little conflict within their

inner network of support. Kirschling and others (1990) apply social exchange theory in an attempt

to understand or explain this behavior. For example, one possible explanation could be that in

cases of terminal illness, individuals tend to minimize the reporting of conflict in order to reduce

tension within relationships and avoid appearing "ungrateful." Picot and colleagues (1997), in

looking at religiosity and perceived rewards of black and white caregivers, hypothesized that

perceived rewards would be based on situational and demographic factors. In finding that white

caregivers perceived fewer rewards than did black caregivers, they noted that whites may perceive

greater cost to their careers or incomes when they are required to become caregivers. Interpersonal

relationships can be sources of various rewards, as well as sources of conflict, and these can be

influenced by demographic and situational factors.

Wilson (2000) addresses how social exchange theory has been applied to the realm of

volunteering, to explain what motivates people to volunteer. He states that social exchange theory

argues that people weigh benefits and costs in deciding to volunteer, and that ability to volunteer is

also based on resources. For example, it is harder to recruit volunteers to work with those with

AIDS, due to the stigma attached to this disease (Snyder, et al., 1999), and volunteers are more

likely to drop out if they do not feel they are receiving rewards with their work (Field and Johnson,

1993). However, Wilson states that exchange theory in itself is not sufficient to explain

volunteering because it assumes individuals make decisions in isolation from their environment,

when in fact they do not. People assess their environment, resources, and formal and informal

networks, all of which help to create a sense of solidarity in their actions. He states that social

resources help to explain why people of higher socioeconomic status volunteer more, and social

networks promote more volunteerism, as well. Wilson (2000) indicates, for example, that those

who attend church more frequently are also the ones who volunteer more.

Feminist Theories

The issue of gender as a variable in the analysis of social phenomena arose with the

contemporary women's movement. While there are numerous feminist theories, many of them

address and explain such issues as gender difference in sex role socialization and economic and

social inequalities. For example, liberal feminism uncovers sexism, and the attitudes associated

with it, as a primary cause of gender inequality. Marxist feminist thought draws upon the works of

Marx and Engels, and it argues that the status of women is based on the economic system of

ownership and private property (Farganis, 2000). Radical feminism cites the use of social

institutions as "tools of male domination which support patriarchy and the oppression of women"

(Farganis 2000:370). Feminist theory rejects biological differences as a significant cause of gender

inequality, and instead maintains that these inequalities are a result of social organization. Some

areas of feminist thought interpret social institutions as perpetuators of male dominance and

patriarchy, which teach women to subjugate themselves and men to dominate. The social spheres

are seen as influencing the "private" sphere of family.

In relation to caregivers, Olesen (1989) states that issues of gender, race, and class require more

attention. She states that critical issues regarding informal health care workers are neglected.

Because women are socialized into the caregiving role and are more frequently caregivers than are

men, she expresses concerns about women and equity in work and caregiver roles. Issues of stress

and the economics of care are important to consider because the "hidden providers," as Olesen

(1989) calls them, are important producers of health in our society. She states that women should

contribute to framing policies about care. As more women become a part of the paid labor pool,

this may result in a diminished pool of caregivers, unless more males are willing to share in this unpaid work. Gender stratification and the division of labor are important in sociological analysis, because they influence how our society functions in both paid and unpaid work, including care for the terminally ill.

Gender differences in religiosity have also been noted in past studies (for example, Walter and Davie, 1998), which report that females tend to be more religious than males. Walter and Davie (1998) indicate concerns regarding women submitting themselves to the patriarchal institution of religion and how that may influence their behaviors and feelings, including feelings of guilt fostered by some religions. The ideology of sacrifice is especially prominent in religion according to Walter and Davie (1998), and women are taught that "it is a good thing that they sacrifice pleasures, careers, income, life itself" for the sake of others (p.650). Differences in socialization translate into differing roles in both the workplace and the home. Walter and Davie (1998) also indicate that women encounter death disproportionately as mourners, as well as carers, because they very often outlive their spouses (p.652). Finally, they note that as we move into these postmodern times, a shift is occurring towards a more spiritual focus and away from more authoritarian forms of religion. Walter and Davie (1998) indicate that this new form of worship is "more truly spiritual…noticeably female in both structure and leadership," (p.655) and one in which the self replaces the church as spiritual authority. This shift in spiritual focus is likely to influence gender roles, as well. It is important to attempt to understand health, illness, coping, caregiving and religiosity in terms of social influences, as well as it how it is experienced differentially by men and women, and that brings us to the next discussion, on phenomenology.

Phenomenology

Phenomenology can be considered one variety of the perspective known as symbolic interactionism, which is addressed next. Its emphasis is on understanding human consciousness as it relates to human interactions. Phenomenology can be characterized as a theoretical framework that "seeks to understand the world from the point of view of the acting subject and not from the perspective of the scientific observer" (Farganis 2000:311). It examines the content of our consciousness about our social world or social reality. Observational techniques are employed by phenomenologists to gather their empirical data. The social construction of our reality is an important theme for phenomenologists. Berger and Luckmann (1966) indicate the purpose of this type of analysis is to understand everyday life, which involves a subtle interchange of subjective meanings. The social construction of reality builds upon Max Weber's (1968) concept of *"verstehen"* (German for "understanding"). Weber states that we cannot fully understand individual behavior without having some sense of how people subjectively interpret their behavior. This insight calls upon sociologists to use more of a subjective or empathetic approach to understanding social life. Phenomenology refrains from any causal or genetic hypotheses, according to Berger and Luckmann (1966).

Subjective meaning and the social construction of meaning can be found throughout the literature on religiosity, spirituality, and caregiving (Glik, 1990; Park and Cohen, 1993; Parker-Oliver, 2000). The importance of gender, race, socioeconomic status and other demographic differences in influencing experience are also emphasized. In particular, qualitative studies make an attempt to explore differences in subjective meaning for differing groups of people. Glik (1990) addresses the social construction of spiritual healing through the use of participant-observation in healing groups, that were designed to help people heal emotionally, physically, or otherwise. Her results showed that problem redefinition often leads to individuals perceiving themselves as healed. This study reflects the importance of understanding how subjective experience influences

perceptions of situations. It also addresses the role of groups in impacting or influencing individual perceptions.

Symbolic Interactionism

The writings of George H. Mead (1934) influenced the symbolic interaction perspective, with his notion of the individual as an active and reflective social actor in interactions. This school of thought "emphasizes social and interactive processes that allow individuals to construct their actions" (Farganis 2000:349). Individuals interact, communicate, and develop shared meanings in their everyday life, according to the symbolic interactionists. Parker-Oliver (2000) states that in looking at death, symbolic interaction holds that our conceptions of death and where and how the dying process occurs are all social constructions. Meanings shape our experiences of death, and the experiences influence our meanings, according to this perspective. Moreover, the "definition of the situation" (a concept developed by William I. Thomas, 1928) changes over time and across situations, as individuals reinterpret events and give them new meanings. This concept refers to how people perceive situations in their lives and how that perception shapes their experiences. The definitions we give to situations are the real forces that shape our behavior (Thomas, 1928). Therefore, in dealing with dying, at one point in time caregivers may perceive dying fearfully, and may then later see it differently, and deal with it differently based on their redefinition of the situation. The hospice community can act as one reference group that assists with the interpretation process and redefining death. Goffman was another influential individual in the field of symbolic interactionism, and his contribution of the dramaturgical model is addressed next.

Dramaturgy

Parker-Oliver (2000) applies Erving Goffman's dramaturgical model to the hospice setting. She indicates that the hospice community helps to bring the drama of dying to an appropriate close. According to Goffman (1973), in everyday interactions, the setting, appearance, and the staging of the drama are all important. The *setting* for hospice is usually in an individual home or sometimes

in a nursing home. The *stage* is usually the family's living room or a bedroom, and the *props*

include a hospital bed, wheelchair, bedside table, urinal, and other medical equipment, which all

become part of the *dying role*. *Appearance* concerns appropriate interactions for the role. For the

hospice caregiver, the appropriate appearance would be one of "engagement, warmth, concern, and

compassion" (Parker-Oliver 2000:505). The *manner* taken on by hospice staff is one of

competence and knowledge about death and the dying role. Hospice helps the dying individual to

fulfill the dying role by assisting them in finding hope, new meaning, and giving them a sense of

control, according to Parker-Oliver. One way they do this is by controlling the patient's pain and

working to manage physical symptoms. Hospice also prepares the family and patient for death by

educating them about the signs and symptoms of impending death. When these physical signs

appear, Parker-Oliver states that the "final deathbed scene" (p.509) begins. The active dying

process is identified, and the hospice community helps to prepare the family for "saying goodbye,"

dealing with feelings, grieving, and letting go. The hospice nurse is frequently present at the time of

death and contacts the funeral home, and prepares the body by cleaning it. They provide comfort

and consolation at the funeral and continue bereavement support after the patient has died, for up

to a year. This study demonstrates how hospice plays a role in facilitating the dying role and

helping the "actors" to perform it, and illustrates Goffman's dramaturgical model.

Attribution Theory

   Numerous studies build upon the social-psychological concept of *attribution* in shaping their

theories of coping (Lazarus and Folkman, 1984; Pargament, 1990; Park and Cohen, 1993; Spilka

and Schmidt, 1983; Spilka, et al., 1985). Spilka and Schmidt (1983) indicate that an attribution is

simply an explanation for an event's occurrence. Attribution theory "is primarily cognitive in

nature, and assumes a fundamental human propensity to make sense out of the world, to

understand the causes of events" (Spilka and Schmidt, 1983). Spilka and colleagues (1985) suggest

that attributions are made for three basic reasons. First, they provide meaningful explanations of

reality. Second, they allow one to exercise cognitive control over outcomes. Finally, they are used

to maintain and/or enhance self-esteem. Again, the basic assumption in attribution theory is that

people attempt to make sense out of their experiences. In doing so, individual *appraisals* of events,

rather than merely the events themselves, are important according to attribution theorists. This

notion is similar to the "definition of the situation" concept developed by W. I. Thomas. Some

individuals use religion to provide meaning-enhancing explanations of events, according to the

attribution theorists. Spilka and Schmidt (1983) and Spilka and colleagues (1985) indicate that the

characteristics and context of the attributor are important to consider. Individual, situational, and

contextual factors all play a role in determining whether an individual uses religious or non-

religious attributions in applying meaning to their experiences. For example, in their 1983 study

(p.331) they found that attributions to God are made more frequently the more important the event,

and if the event is medical as opposed to economic or social in nature. They also note that "positive

events elicit stronger attributions to the deity than do negative happenings. In like manner, serious

occurrences stimulate slightly stronger God attributions than events of lesser significance" (Spilka

and Schmidt 1983:334). This shows how characteristics of the event can influence attribution.

Social coercion might also influence attributions, in that "if attributors believe that other people

will like them more if a particular attribution is made, they will be more likely to adopt that

attribution strategy" (Spilka, et al. 1985:13). In other words, the attributor may choose a particular

attribution based on the approval and positive regard of others if doing so will increase their self-

esteem.

Characteristics of the attributor, such as locus of control, doctrinal orthodoxy

(fundamentalism), and intrinsic or extrinsic religiousness are influential in making attributions, as

well (Park and Cohen, 1993). Park and Cohen (1993) build on the cognitive model of coping

developed by Lazarus and Folkman (1984) and address intrinsic and extrinsic religiousness in

influencing attributions. They indicate that intrinsic religiousness "regards faith as a supreme value

and as providing one's life with motivation and meaning" (Park and Cohen 1993:562), while

extrinsic religiousness is influenced by external motivational variables, such as social standing,

safety and comfort, rather than being faith-guided. Their findings indicate that intrinsic

religiousness (based on faith and meanings) plays an important role in the coping process and is a

positive predictor of personal growth. Park and Cohen (1993) also found that those who make

attributions to a purposeful, loving God in coping with death experience less distress than those

who do not. In addition, doctrinal orthodoxy (fundamental beliefs) seemed to serve a protective

role. Doctrinal orthodoxy was associated with increased use of spiritual support coping (reliance

on one's personal relationship with God) and predictive of less event-related distress. In other

words, these individuals rely on their relationship with God as a source of support in coping. The

studies tend to lend support to the notion that attributions to God are a function of both individual

and situational variables. Attribution theory takes into account the power of contextual factors,

which can strongly influence attributions and meanings in coping.

SUMMARY

Much research has been conducted on caregivers and the stress and coping processes. Studies

indicate that both stress and coping involve *processes*, which are based on the interactions of

individuals with their environment and resources. These processes involve *attempts* at dealing with

difficult situations. Some attempts at coping are more negatively focused, while others are more

positively focused. Personal and situational factors also influence the coping process. Race, gender,

age, length of time spent as a caregiver, and other individual characteristics can affect how a

person copes, and their access to resources. The involvement of religion or spirituality in coping

will depend upon the individual's previous experience and belief systems to which they have been

exposed.

Previous research on caregiving focuses primarily on family or unpaid (informal) caregivers and

on paid (formal) caregivers, while little research has been conducted about the experiences of

hospice volunteer caregivers. This study seeks to fill a gap in the caregiver research by looking specifically at the experience of hospice volunteer caregivers. The use of qualitative research is best suited for exploring and understanding the experiences of the hospice volunteer caregiver so that volunteers may explain their subjective experiences in hospice work. Focus groups were used in order to gain a richer, more detailed understanding of their experiences. A brief participant survey was administered in order to gather demographic information. The current study builds on previous research on hospice volunteers conducted by Field and Johnson (1993). It focuses on whether hospice volunteers are a particularly spiritual or religious group of people, and if so, how religion or spirituality manifests itself in their work. Hospice volunteers play an extremely useful role in assisting caregivers of the dying and the patients themselves with daily care, emotional needs, and spiritual needs. Understanding the types of issues that volunteers face can assist hospice agencies in providing support for volunteers to ensure that they have a positive experience and will want to continue volunteering.

CHAPTER III

METHODOLOGY

I chose to make use of focus groups in conducting my study. Focus groups were appropriate for this research because they provide the opportunity for an in-depth understanding of the experiences and attitudes of people (Krueger, 1994). People develop their attitudes and perceptions in interactions with others, and focus groups allow the interviewer to tap into these interactions and understand the perceptions of a particular group of people, in this case hospice volunteers. The environment of a focus group generally is nonthreatening and provides a comfortable, and perhaps enjoyable, space for people to express their ideas (Krueger, 1994). Finally, in focus groups, the moderator and the respondents have the freedom to explore areas that they would like to discuss, rather than being limited by closed-ended response choices used in a questionnaire. Focus groups allow the respondents to explain what they mean when they give an answer to a question. The procedure, sample, interviews, and data analysis are discussed respectively in this chapter.

PROCEDURE

Information for this study was collected in three face-to-face focus group interviews, using a semi-structured questionnaire. The focus group interviews took place at the location of each hospice organization for which the volunteers worked. Each focus group interview lasted between one and one-half to two hours.

After explaining the interview process and asking for any questions, written informed consent (see consent document in Appendix A), which included a request to make an audio tape recording of the interview, was obtained from each participant. Participants were informed that all data

50

would be kept confidential. A participant survey (see Appendix B) was also given to each respondent for completion at the end of their focus group interview. This sheet was used to prepare demographic profiles for the respondents, including information on age, income, gender, race, duration of time as a hospice volunteer caregiver, religious denomination and self-perceived extent of faith. A list of caregiver support group phone numbers for the area was provided after the interviews, in case any of the respondents should require support assistance in relation to the discussion topic of the interviews.

SAMPLE

The sample for this study consisted of hospice volunteers for three different hospice organizations. The three hospice agencies at which the focus groups were conducted included one non-profit hospice agency, one for-profit agency, and one agency that was affiliated with a major hospital system. Two of the hospice agencies were located in a large Texas city (approximate population of 660,000), and one agency was located in a small Texas town (approximate population of 4,800). The total sample size was 15 individuals, of which 12 were females and three were male. The sample was one of convenience. Because the sample was non-random, the results of the study will not be generalizable to all hospice volunteers. I asked Volunteer Coordinators from three separate hospice organizations to assist with the sample selection process. They contacted the volunteers to arrange for the focus groups that took place at three separate times and locations in October of 2002. Pseudonyms are used in place of actual names to protect the anonymity of the respondents.

I attempted to attain a diverse group of respondents by age, gender, race, income, religious belief, and education level. However, all of the volunteers were white, and 12 of the 15 were female. Age of the respondents ranged from 37 to 79 years old, with an average age of 64. The reported marital status for the sample included two single individuals, eleven married individuals, and two divorced/separated individuals. The sample included a variety of religious preferences,

including three Lutherans, two each of Catholics, Church of Christ, and Presbyterian, one Methodist, one Episcopalian, two who indicated no religious preference, and two who were non-denominational. Education level reported included one who had completed through high school, seven who had completed some college, and seven who had college degrees. Ten individuals had yearly net income of $35,000 or above, while two did not answer the income question, and three reported yearly net income of less than $35,000. Duration of service as a hospice volunteer caregiver was 6 months to one year for one individual, between one to five years for seven, and greater than five years for seven of the respondents. Specific demographics by group are discussed next.

The first focus group consisted of four white females. The age of the respondents in group one ranged from 37 to 60 years old. One was single, one was divorced, and two were married. Two reported having some college education, while the other two had college degrees. They all reported different ranges of net level of income (from less than $15,000 to more than $45,000). Duration of service as a hospice volunteer caregiver was between one to five years for two from this group, and greater than five years for the other two. Religious preference included one no preference, one non-denominational, one Catholic and one Methodist.

Group two consisted of two white females and one white male. The age of the respondents in group one ranged from 42 to 68 years old. One was single, one was divorced, and one was married. All three reported having some college education. They all exceeded $35,000.00 net level of yearly income. Duration of service as a hospice volunteer caregiver was 6 months to one year for the youngest participant in this group, between one to five years for the 54 year-old, and greater than five years for the 68 year-old. Religious preference included one non-denominational and two Lutherans.

The third focus group consisted of six white females and two white males. The group three age range was 56 to 79 years of age. The third group consisted of mostly retired individuals, and only

one person in that group was under the age of 60, while most were over 70. All eight of this group reported themselves as married, with a few indicating they had been widowed and had remarried. Highest education levels reported by this group included one with a high school education, two with some college, and five who had college degrees. Two did not report their income level, while one earned less than $35,000 in net yearly income, and the rest of the respondents earned over $35,000. Four respondents in this third focus group had between one to five years of service as a hospice volunteer, and four had served for greater than five years. Religious preferences most commonly indicated by this group were Presbyterian and Church of Christ (two of each). The other four individuals reported their religious preferences as Episcopalian, Catholic, Lutheran, and no religious preference.

INTERVIEWS

The purpose of using semi-structured interviewing was to allow more detailed information to surface that might not be present if the respondents completed a survey. This loosely guided interview process allowed for examination of the subjective reality from the point of view of each participant. Each group was asked the same set of questions, with additional probing questions added, as appropriate to the experiences discussed by each group (see Appendix C for the interview schedule). At the beginning of each focus group, I asked participants to introduce themselves and state how long they had been a volunteer caregiver, as well as anything they wanted to tell about themselves. I also asked them to explain why they got involved in hospice. Next, I asked about particularly stressful or difficult experiences as a hospice volunteer caregiver, and what was most helpful to them in coping with these experiences. Then, I explored their perceptions of the dying process and the role of religion or spirituality in their appraisal of it, and asked how their perceptions of death had changed since becoming a hospice volunteer. In closing, I asked them if there was anything they would like to add to describe how they felt about their experience as a hospice volunteer. Probes (i.e. follow-up questions) were included as needed to further explore

particular topics that arose in the interviews. If the participants appeared to want to go in a particular direction that related to the topic, I allowed the interview to flow with the structure they established rather than staying with a pre-established structure.

DATA ANALYSIS

Once the interviews were transcribed, I performed content analysis on the data. Content analysis allows one to look for themes and patterns that emerge in the interview transcripts. It allows a means of quantifying what was said in the groups and determining those themes and patterns that occur most frequently. As the interview transcripts were analyzed through content analysis, key words and phrases were used to help sort the data with the original research questions as guides. Initial coding categories were established, during and/or after the transcription process, for the purpose of sorting the data according to major themes. Segments of the text were labeled to fit into the following general categories: demographic information, stressors and impact of stress, coping and support (including religious and spiritual coping), family dynamics, types of care, rewards and reasons for doing hospice work, dealing with death and finding meaning, and connections or ties with patients. The transcripts were reviewed multiple times to ensure accurate categorization of the interview segments. Key words in respondents' phrases were sorted according to the categories established, or were used to develop new coding categories if needed. Some overlap among categories occurred because they are not always truly distinct categories. For example, finding ways of connecting with the patients could also be considered a type of coping. Finding meaning in dealing with death can also be considered a coping strategy. However, because dealing with death and connecting with patients were frequently referred to by the respondents, they are addressed separately.

Chapter IV addresses the findings from the three focus group interviews. The findings will include an analysis of the present data in relation to past research and sociological theory.

CHAPTER IV

FINDINGS

Eight themes and patterns emerged in the interviews: demographics, types of care, stressors and

impact of stress, family dynamics, coping and support, rewards and reasons for involvement in

hospice, connections or ties with patients, and dealing with death and finding meaning. As

previously mentioned, some overlap occurs between the categories.

DEMOGRAPHICS

Summary information is provided in Table 1 (pp. 60-61), entitled "Focus Group Participant

Demographics and Types of Care." As noted, in Chapter III, actual participant names are replaced

with pseudonyms. Some of the hospice volunteers interviewed had occupations that involved direct

caregiving of some type, while others had non-caregiving related occupations or were retired from

paid employment. Oscar, who was originally raised in Arkansas and later moved to Texas, did not

indicate what type of work he had retired from, but said he likes to do handyman jobs currently,

although he has some problems with arthritis. Clint, Penny's husband, had served as a medic in

World War II and afterwards, then said he "decided I was never gonna punch a time clock, so I got

a peddler's job. And I did that 'til I retired." Penny also commented that Clint had done a lot of

volunteer work with the VA after his retirement. Julie is a housewife. Ellen is a retired school

financial counselor. Yvette, retired, indicated she originally came from New Zealand, and "I've

lived here in Texas a long time." Julie indicated involvement in an organization called *Friends of*

Hospice, which is "kind of the auxiliary, you might say, of hospice. *Friends* is a separate group that raises money." Yvette and Beth also indicated involvement with *Friends of Hospice*. They indicated that the funds raised are used to help indigent patients. Ellen called herself a "transplant from New England. Been here 29 years in Texas." She said she had no family left except for a daughter who lives in New York. Ellen's mother, father, and brother had all passed away. Several from the third group, including Beth and Yvette, had lost spouses. Some remarried. For example, Penny and Clint were neighbors who both lost their spouses, then eventually married each other.

TYPES OF CARE

The hospice volunteer caregivers in this study performed diverse types of care. A brief summary of respondent demographics and the types of care provided by each respondent is included in Table 1, on pages 60 and 61. Because volunteers are not trained medical professionals, they cannot provide medical care or administer medications, but they do provide all other types of assistance, including physical, mental, emotional, and spiritual support.

Physical care can include direct patient care such as lifting and moving the patient, helping the patient get onto a bed pan, and changing patient briefs. Other tasks included performing CPR (cardiopulmonary resuscitation) or working with breathing equipment if the patient had trouble breathing, calling for professional help when emergency medical situations arise, and massage work on the patient. Some respondents also mentioned feeding the patient or pleasure-related tasks such as taking the patient for a drive. Dave reported closing the eyes of a deceased patient and cleaning their body. Jan said she manicured a patient's nails twice a week. Breathing with the patient was another form of physical support (also could be considered spiritual support), which purportedly helps to calm and relax the patient, according to Sally. Physical support to the family caregiver includes such activities as respite care (being present so that the caregiver can tend to other tasks), housework and cooking, running errands, or massage work on the caregiver. Beth, the chaplain, mentioned cooking meals for her patients. For example, for "Jeff", an ALS patient (ALS

is addressed further below) that passed away recently, she would prepare a monthly meal of chicken and dumplings, and invite family and friends to have lunch with him. Jean mentioned that learning to read lips was a helpful skill with ALS patients, as they eventually become unable to speak. Types of care mentioned, therefore, were varied, and some were more pleasure-oriented, while others more instrumentally focused.

Caring for patients with ALS was one of the more challenging tasks faced by the volunteers. ALS stands for Amyotrophic Lateral Sclerosis, also referred to in North America as "Lou Gehrig's disease," because of the famous New York Yankees baseball player who died from this disease in 1941 at the age of 38. ALS is a progressive, motor neuron disease that affects the nerves coming from the spinal cord responsible for supplying electrical stimulation to the muscles of the body. Without this stimulation, movement of the body parts is limited or halted altogether (MedicineNet.com, 2002). ALS patients require almost constant monitoring and care in the later stages of the disease and are often assisted by breathing equipment.

Mental, emotional, and spiritual support categories tend to overlap with one another to some degree. An example of mental support for the patient or caregiver includes providing information about the progression of stages for the disease they are facing. Mental support can additionally include information about outside support contacts or information about how to deal with particular issues that arise, such as communication problems between caregiver and patient. Emotional support includes counseling, companionship, encouraging, talking with, or simply listening to the patient or the caregiver. Rebecca stated that she provides grief and general counseling. Volunteers also can provide bereavement support to the caregiver after the passing of the patient. The volunteers in this study also mentioned being there to hold or touch them as a source of comfort. Ellen said "Some just want to be touched. 'Just sit there and hold my hand' " was the message she received from some. Dave reported providing emotional support for the caregiver while waiting for the hospice nurse and mortuary to arrive after a patient died in his

presence. Caregivers often need assistance with processing feelings, and the volunteers were present to listen to, accept and support them. Julie said "everybody is different, and you're fine if you listen or you talk or you read or just be there." Julie said she always takes flowers to patients and Ellen always brings them angels. Therefore, mental and emotional care can be cognitive, such as providing support for emotions, or behavioral, such as touching someone or giving a small gift to cheer them.

Companionship included playing games or other activities with the patient, which arose as a frequent theme in the third focus group. For example, Oscar played dominoes every Thursday afternoon with one patient. Oscar also watched TV, sometimes ballgames, with patients. Beth worked crosswords with Jeff, an ALS patient. Julie said one patient was so good at playing Canasta that she played with five decks of cards. Companionship also included just being there and listening to the patient, and hearing stories. In fact, Beth audio taped the life stories of one of her patients, and also made a typed transcript, to leave a legacy for the family: "So I brought my little Sony recorder, and I got her to tell her life, to leave for her kids and for her grandkids. And we just had the most wonderful time then." One of the patient's stories Beth shared was about the woman's family picking cotton together, and although it was hard labor, how much she enjoyed it as a time spent with her family. Sheila provided audio taped versions of popular books for Jeff to listen to when he could not hold a book anymore. Sheila, Penny, and Beth shared in doing volunteer work for Jeff, the ALS patient, since he required constant care, and this allowed his wife some time to get away. Companionship and sharing were common types of care provided.

Spiritual or religious forms of care include reading the Bible or other inspirational readings to the patient, prayer, breath work (breathing with them to help them relax), singing (faith songs were mentioned), and massage. Rene, the nursing student, indicated that patients she has worked with have requested that she sing to them. Dave said he would sometimes sing faith songs. Sally and Kate are both trained and licensed for massage work and provide massage to their patients or

caregivers when a physician order has been obtained to do so. Additionally, many of the respondents frequently recounted being there to listen to the patient or caregiver as a type of care. Talking with the patient or their caregivers about death and the afterlife was another form of spiritual care they provided. Patients often felt comfortable opening up about their fears and guilt about past mistakes with the hospice volunteers. By listening to and talking with them, the volunteers often provided a safe space for them to heal issues that needed to be resolved.

The respondents performed all different types of care in their hospice volunteer work. Emotional and spiritual support were prominent themes in the interviews. The use of spirituality by the respondents appeared to be a frequent occurrence, when appropriate and acceptable to the patient or caregiver. These data will be addressed further in the "Coping and Support" section of this chapter.

TABLE 1 – FOCUS GROUP
PARTICIPANT DEMOGRAPHICS AND TYPES OF CARE

Pseudonym	Focus Group	Type of Caregiving	Years of Volunteering	Occupation
Rene	One	singing reading listening errands spiritual care	1-1/2 years	Nursing student
Joan	One	physical care errands emotional care spiritual care	3 years	Computer corp.
Sally	One	breath work spiritual care	17 years	Massage therapy/ meditation workshops
Kate	One	massage emotional care spiritual care	7 years	Insurance Invest./ Massage therapy
Rebecca	Two	respite care counseling spiritual care	< 1 year	Bookkeeper
Jan	Two	respite companionship chores physical care listening spiritual care	4 years	Office manager
Dave	Two	respite bereavement physical care emotional care spiritual care	6 years	Retired Marine

TABLE 1 - CONTINUED

Pseudonym	Focus Group	Type of Caregiving	Years of Volunteering	Occupation
Yvette	Three	fundraising	7 years	Retired
Sheila	Three	physical care emotional care spiritual care	5 years	Retired government employee
Beth	Three	recording patient's life; emotional care cooking spiritual care	5 years	Former: Legal Secretary/ Present: Chaplain
Ellen	Three	physical care emotional care gives angels	2 years	Retired Financial School Counselor
Julie	Three	emotional care gives flowers	8 years	Homemaker
Oscar	Three	companionship	1 year	Retired/ Handyman
Penny	Three	physical care emotional care	6 years	Retired Respiratory Therapist
Clint	Three	unknown	6 years	Former Medic/ Peddler

STRESSORS AND IMPACT OF STRESS

The respondents in this study mentioned stressors for themselves and stressors that the patients experienced more frequently than they did family caregiver stressors. Sources of stress for the respondents related to family dynamics (which are addressed later in this chapter), fear of hurting the patient, fear of doing something "wrong," and seeing the patient in pain. Additional stressors included talking about death and the afterlife, culture clashes, trouble with maintaining detachment when appropriate, and emotional strains. The respondents indicated that the patients had stresses such as confronting illness and death, dealing with family members, feeling like a burden, facing guilt and other difficult emotions, and concerns about leaving family members provided for. Finally, family caregivers had to face trust issues, according to the respondents, in leaving the patient with a volunteer caregiver, so that they could take time away for themselves. The primary caregiver often felt obligated to stay and be there for the care receiver at all times, according to the respondents.

First, I will address stressors experienced by the respondents themselves, in relation to concerns over the patient. Sally voiced one of the concerns she experienced in hospice volunteering, which was her worry about physically hurting the patient. She stated, "I'm afraid to turn them or afraid I'll hurt them, and I don't want to hurt somebody. It just hurts me to hurt somebody physically." Concerns about patient pain or discomfort was also a source of stress, according to both Sally and Kate. Kate, in speaking of being with an acquaintance she was with, who died before she became a hospice volunteer, said:

> He was doing the agonal breathing at the end, …and no one had explained to us
>
> what to expect. And I was standing over the bed watching him, and my feelings
>
> were *he looks uncomfortable .. I should be doing something.*

Sally explained the discomfort of seeing someone in pain:

> When somebody is in pain or something, you don't want them to be in pain... but
>
> if they make a noise or something, everybody thinks *pain, give them some more*
>
> *medicine, they're in pain, I know they're hurting.* And it's us watching that it's
>
> really hard for.

Being there when a patient dies under their care can also be a tense situation, when the volunteer is

the only representative present from the hospice agency. Dave talked about his experience with

being there without other hospice representatives:

> I've even had to close the eyes of one that died. In fact, I've had three different die
>
> under my care, on my watch, and it's kind of nerve-wracking. Especially when
>
> you're trying to get the hospice nurse up there, and she's in South [city name
>
> removed] in 5:00 traffic trying to get up there (laughs)....[you] get used to it....it
>
> is kind of stressful, I guess, but you just kinda...just keep praying...(laughs).

Several in the third focus group had worked with ALS patients. ALS patients are an exception

in the length of time for which they can receive hospice care. The volunteers that worked with Jeff,

one ALS patient, said they'd been working with him for ten years when he died. Beth said that

ALS patients "officially have to be discharged," from hospice if they are not dying, but still receive

care. Sheila and Beth both worked with Jeff, and expressed fears about him choking and having

trouble breathing. Sheila's concern was expressed this way: "I still am always concerned when I go

out there, because usually I'm there by myself." His wife usually will leave to take care of errands.

One time she had to call his wife home and the wife "just went whomp" [indicating a chest

maneuver related to CPR]. "She did it much harder than I did, and then he was alright. But I mean,

those are things that you get concerned about." She also voiced a concern about the electricity

going out and having to switch over to battery power within a minute on his breathing machine,

called a bi-pap. Beth, the hospital chaplain, expressed her trepidation when her ALS patient, Jeff experienced some breathing problems:

> [He] got out of rhythm with his bi-pap…as long as he stays in rhythm (breathing)
>
> with his bi-pap, well then he's fine…that's the only time it ever happened when I
>
> was there…he got scared in front of me.

Penny, another respondent in the third focus group, also worked with Jeff but felt more comfortable with the breathing issues because of her background as a respiratory therapist. Julie worked with a female ALS patient, and also felt that working with "an ALS patient is very intense." She was unskilled in handling her (the patient) for use of the bedpan and said that made her feel like she "did a lousy job." She added, "Fortunately, a couple of the other volunteers were nurses, and so they knew how to do that." Patient pain, discomfort, and death were all mentioned as sources of anxiety that the respondents became accustomed to dealing with as they spent more time doing this line of work.

Beyond concerns for the patient, there are self-concerns and stresses associated with overwork and needing to take a break from volunteering. One respondent, Joan, said she recognized she was feeling burnt out and needed to detach from volunteering for awhile: "I was leaving tired, and I didn't feel like I had done anything worthwhile that evening. I hadn't shared anything." Sally noted that she felt burnout can definitely occur but usually more frequently for those who feel they are there to *help* someone as opposed to just being *present* with them:

"I think some volunteers do burn out though, and I don't know … you know, I have my ideas (laughs)…on why…but it's just…when you go in so much to be the helper versus being there." Burnout is one source of stress volunteers can face.

Stressors for hospice volunteers can also result from difficult patients or from culture clashes. However, a volunteer's attitude can influence how the situation is perceived. For example, Rene, in

discussing a more difficult and controlling patient, said:

> ...it started off as not a very good relationship because she was very, you know,
>
> controlling and.... And I guess that's the other thing, is that you find all these
>
> different personalities—not always pleasant—but it never seems to be a negative
>
> thing. It seems to kind of transcend what ... you know, would ordinarily make me
>
> angry or upset or whatever.

Rene also mentions another patient that she found to be trying:

> ...sometimes, you know, you have joy with your patients, and sometimes you
>
> don't. I have a patient right now, currently, who's in a horrible situation. She's in
>
> a nursing home. She hates being there. She's manipulative. She's definitely a
>
> pain...

Rene, however, indicated a commitment to seeing this woman, and felt it was the right thing to do, despite the difficulties encountered in being with her. In addition to difficult personalities, culture clash can be another stressor for volunteers. Dave, the former Marine, stated:

> I had one Hispanic gentlemen...he said 'I don't want no gringos taking care of
>
> me...get out!'... The older son was the caregiver, and he needed some help. They
>
> had eight children....but that's the only one he allowed to help him.

He indicated he had to honor the man's wishes and withdrew from volunteering for that family. Dave also stated that he had a preference to not work with women in nursing homes, as he appeared to find them particularly challenging:

> I have to admit that there are some patients I can't cope with. And that's a lady in
>
> a nursing home. I cannot deal with ladies in nursing homes.... they're incoherent.
>
> They're not ... they're on the fringe, as well...

Some patients are more difficult to deal with, which may relate in some degree to their environment. For example, patients who are in nursing homes may be more unhappy with their

situation than those patients who are receiving hospice care at home. Although this issue of home

care as compared with nursing home care was not specifically addressed in the interviews, it could

be a potential area to explore in future research. The stresses experienced by patients and

volunteers are likely to differ in these two differing environments.

Talking with patients about death can also be a source of potential stress for hospice volunteers.

Perceptions of death and confronting death are further addressed in a later section of this chapter.

However, I will note here that some the volunteers indicated that when they lose a patient it makes

them very emotional. Jan said, "When your patients die, it does put you in a very weird space for a

while." It takes awhile for them to face the death and process their grief, and realize that the patient

has really passed.

The respondents also addressed patient or family caregiver stressors. Sheila stated that one

woman she served as a volunteer for, had a paid young female caregiver that "had forged checks

on this lady's account [and] it really hurt the lady, because she was really crazy about her." Sheila

indicated that the woman went through a series of paid caregivers that stole from her. Sheila said

she tried to maintain some distance from the issue, but it hurt her to see the woman being treated

that way. Family stressors were also common. Although they frequently mentioned trying to

maintain a certain amount of detachment from family issues, the respondents would often be

emotionally available to help the patients deal with personal difficult emotions associated with

illness and death. These included upsets with family members, feeling like a burden, facing guilt,

and concerns about leaving family members provided for. Patients frequently verbalized their

concerns and fears with them, according to the respondents. The respondents indicated that the

patients often needed to process their anxieties or sometimes avoid them by talking about

something else. For example, Rebecca addresses the patient's need to sometimes just forget that

they are sick:

> Yeah, a lot of times I found that... being that they've been around the caregiver
> night & day, 24/7...that that part of their life – they just really – they don't wanna
> think about how sick they are or when they're gonna die or...They wanna just
> share what they have left with someone.

Guilt and difficult feelings create an enormous amount of anxiety for some patients who regret their past actions. Jan had one patient who was an alcoholic and was dying from alcohol-related diseases:

> .... But, he is processing all of what he should have done and should not have done
> with his children, who are in their 20s, and has lots and lots of guilt feelings about
> – that he wasn't there when ... he divorced his wife – he left the kids with her
> because he knew he couldn't take care of them because his life was so messed up.
> One of his sons ended up committing suicide, and that's really hard for him
> because he thinks he may have been part of the cause.

Burdens from the past can be difficult for patients and being able to discuss these issues with someone often helps to relieve them.

Patients frequently process feelings and share their lives with someone who is coming in with a fresh perspective on them, not carrying in past perceptions of who they think the patient is. This provides some relief for the caregiver, as well, as Jan points out:

> And sometimes the family has heard what they've said over and over and over,
> and you know, when you're a permanent, full-time caregiver, you're mad half the
> time, and tired and frustrated and worn out half the time. You're getting some
> good things out of it, too. And you [the primary caregiver] feel guilty because you
> feel like you can't do it another minute, and then we come in there, and they can
> get out of the house and that person can say the same old stuff over again, and we
> haven't heard it.

The presence of the volunteer provides some temporary relief for the caregiver. However, they have to sometimes deal with trust issues, and be willing to leave the patient alone for awhile with another person. The volunteers indicated that is sometimes an obstacle that they and the caregivers must deal with in order for them to be able to assist the caregiver. For example, Jan said the primary caregiver wouldn't go take a nap or do something for themselves without having to "kick them out most of the time." Rebecca said, "it's like leaving your two-year-old child with a new babysitter, you know....you don't want to trust them, but you know you have to." Sally mentioned one caregiver wife that had been sitting with her husband 24 hours a day (at a home that provides end-of-life care for AIDS patients), and promised her husband she wouldn't leave; "So she hadn't been home; she hadn't done anything. And they kept thinking he was going to die, thinking he was going to die, and he was actively dying for days." It can be difficult for the caregiver to allow themselves time away, for fear they might not be there in a crucial moment. These stressful interactions require communication and trust-building skills. Sometimes it involves skill at recognizing when to stay out of family issues and let them resolve themselves, knowing when to step in and provide support and when to contact the volunteer coordinator if it is an issue requiring hospice agency involvement.

The three major forms of stressors identified by Thoits (1995) were life events, chronic strains, and daily hassles. All three types of stressors appeared for family caregivers, and the respondents indicated assisting in the coping process. The volunteers experienced stressors which consisted primarily of the daily hassles associated with physical care and emotional support of the patients and their families. Stigmatization (Snyder, Omoto, and Crain, 1999) was not mentioned as a source of stress by any of the volunteers. Nor did they report feeling devalued as unpaid workers, as noted for the "hidden" providers, which are unpaid family caregivers in Olesen's (1989) article. However, emotional and psychological strains occurred rather frequently, according to respondent accounts, confirming some studies which also found these strains to be common for family

caregivers (for example, Hull, 1990). The findings of this study confirm stressors similar to those noted by Hull, which included worsening patient symptoms, interactions with others (especially the family), and concerns for self. The latter item, for the respondents in this study, revolved around concerns about becoming burnt out and needing to take a break.

Burnout can occur as a result of role strain, which occurs when a person has been burdened with too many roles or expectations. Role strain was addressed in the Field and Johnson (1993) study of hospice volunteers in the United Kingdom. In their study, nearly a third of the volunteers were working either part- or full-time, while 40% were retired. The current study included seven retirees out of the 15 total respondents. One individual was a homemaker. The other seven respondents in the current study were employed. Some were employed in caregiving occupations, while others did office work and one was a hospital chaplain. One (Rene) was also a nursing student, wife and mother of three young children. The retirees mostly indicated having free time and did not mention stress from other obligations. Because volunteers have a choice as to how often they perform their volunteer work, they have more flexibility when their schedules become demanding. However, sometimes they indicated making commitments and feeling like they should remain committed. Therefore, balancing paid work, school, or ones' family obligations can be a potential source of role strain.

The men and women in this study described communication stressors, confirming the findings of previous research. McGrath and others (1999) addressed dilemmas for palliative care nurses regarding discussion of death with patients. Background and contextual variables, such as duration of caregiving can also influence the level and type of stress encountered (Pearlin, et al., 1990). The findings in this study support Pearlin and colleagues' findings. For example, those with more experience in caregiving (either through a caregiving-related occupation, or longer duration as a volunteer) seemed to feel more relaxed with issues related to providing care. Two of the younger, newer volunteers (Rebecca and Rene) reported strains associated with not knowing what to say or

how to react to certain issues related to family dynamics, for example. As the respondents spent more time as hospice volunteers, they reported learning how to cope more easily with issues that arose. Age and experience with life and death issues seemed to lessen the impact of stress for some.

FAMILY DYNAMICS

Family dynamics was a frequently cited source of stress in hospice volunteering. Social interactions are a source of support but can also be a source of conflict and stress (France and Alpher, 1995; Hull, 1990; Kinney and Stephens, 1989; Kirschling, et al., 1990). Family interactions, as well as any social interactions, can have their costs as well as their rewards. This can be especially true when dealing with the emotionality of family dynamics when coping with dying and death. Feeling caught within family dynamics can be challenging, especially for a new volunteer, as Rene recounted from one of her early hospice experiences:

> ...sometimes it's the dynamic between the patient and the family. It's that synergy
>
> there because the patient by themselves are fine. The family by themselves are
>
> fine. But they're all telling you different things, you know. My first patient, oh
>
> my Gosh, it's like trial by fire.

She recalled that the patient was threatening to commit suicide and telling her about family abuses which of course, she had to report to the hospice agency:

> I'm looking at her family, thinking, *they don't seem like that, but I don't really*
>
> *know. But I'm just a first time hospice volunteer, what do I know.* So I had to
>
> talk about it, and...oh, it was just crazy...and it was just the stress of being in the
>
> middle.

Oscar, the retired handy man from the last focus group, said that the patient will often talk with the volunteer about their family, and the volunteer acts as a "sounding board. And you let them vent some of their frustrations and their.... some of their madness." By being present and listening, the volunteer can help the patient cope with family difficulties.

Frustration with watching the primary caregiver not provide medication on a timely basis also produced anxiety for one volunteer. Jan said one caregiver she dealt with would wait until after his wife was in pain before giving medication, rather than administering regular doses to prevent pain and discomfort. She expressed her frustration with the situation:

> And it's like, what are you going to do, kill them with the medicine? The lady is
>
> dying anyway. Give her her dang medicine. (Laughter)… And that's the way you
>
> feel like sometimes. And it's like you really just want to scream at them
>
> sometimes.

Sometimes it is difficult for patients to talk about concerns with family members. Rebecca indicates it sometimes feels safer for patients to talk with a volunteer:

> They'll be shared with someone that's a stranger…the very personal things. A lot
>
> of times, like confessions- you've found that too (speaking to Dave)– where.
>
> there's guilt or denial or what not, it comes up, and it's easier for them to talk with
>
> a person that they know is there voluntarily and that cares about them, that isn't
>
> going to say anything to the other family members. You know, they feel better
>
> once they get it off of their chest, and you're just there to listen.

Patients also had a hard time relaxing around the family according to Joan, who said when she (the volunteer) arrives, the patient is relieved:

> Because they just had relatives in and out. And say, 'Oh, thank God it's you.'
>
> Because they knew I was there. [With the family] they have to entertain. They
>
> have to sit up, they have to talk, and be strong.

The patient sometimes feels safer to take on that "dying role" with the volunteer, in which they don't have to perform or pretend to be okay. They can just relax. With regards to acceptance that they are dying, Joan indicated and Sally agreed that the patient usually accepts that they are dying

"way before any of the family does." Sally said she tries to be honest with the family rather than going into denial with them, but also accepts them for where they are in their coping process.

The resistance to the "dying role" by family members is also evident in other ways. The family members frequently have a hard time accepting that the patients won't eat, but the volunteers indicate that not eating is common behavior in those who are in the end stages. Joan remarked, "the hardest thing is to explain that it's okay if they don't eat." The family wants them to eat because they are afraid of them dying, and not eating means they are going to die. It's stressful to confront the fact that they are losing them. The family often still sees their loved one in the "sick role," hoping and expecting that they will do what it takes to get better, including eating. Hospice intercedes in an attempt to help families make the transition from the "sick role" to the "dying role" (Parker-Oliver, 2000). This example from the interviews illustrates how the family can sometimes still have hopes that the person will get better (the "sick role"), and have not yet accepted that they are not going to recover (the "dying role").

Resistance to outsiders by the family can be another issue that volunteers have to confront. Sometimes, family members may be ambivalent about having volunteers come into their homes and lives. Lack of knowledge about the services a volunteer provides can be one barrier to family acceptance of them, as Jan noted:

> I don't think they ask, because the nurses are supposed to ask if you would like a
>
> volunteer, and then some people just go, 'Well, yeah, that sounds okay.' You
>
> know. And most people say, 'Well, I don't know what I'd do with one. What
>
> would you do with a volunteer?'.

When the family comes to know more about the benefits of having a volunteer, they then move into acceptance and appreciation for the assistance they provide.

Families often have difficulty with accepting that they are going to lose their loved one, and the volunteer can help relieve some of the tension that occurs due to family dynamics. Kinney and

Stephens (1989) studied caregiving hassles for family caregivers, and reported that minor daily hassles can accumulate into major amounts of stress over time. These minor daily hassles can include Activities of Daily Living (ADL) hassles, such as bathing, lifting, and feeding the care recipient, for example. Family tensions can be high if they are dealing with care recipients who are less able to take care of themselves or require around-the-clock attention. Volunteers are often available to support them, if they are able to apply their skills in a craftful manner. Ways in which volunteers cope and provide support in coping are addressed in the section that follows.

COPING AND SUPPORT

The types of coping used or noted by the volunteers were varied. They included relationship-focused, emotion-focused, and problem-focused strategies, three types of coping mentioned in the literature (Kramer, 1993 and Thoits, 1995). In the current study, emotion-focused coping was less commonly used than problem- or relationship-focused coping. One type of problem-focused coping was to provide education to themselves and to the families and patients about the progression of disease, so that they would know what to expect. Sally indicated that one of her goals for support to families was to provide education about dying:

> ...where it will be like Lamaze classes for dying. (laughs) Where it will just be
> really, really an easy thing... if they go through it and they're willing to be there
> and have them at home, it is almost always you'll hear was a positive experience.
> If they have gotten the education and they go through with it, it's almost always—
> <u>almost</u> always—a beautiful thing.

One skill that Sally put to use was doing breath work, which involves breathing with the patient to calm them. In describing a breathing exchange with one patient, she said:

> When you put noise to your breath... it helps. (Laughs.) It helps you, it helps
> you feel. A big sigh, a big anything. Because she was breathing like that, real
> easy. And I talked to her. She smiled.

She indicated that the breathing calms people and "stops them from being afraid." A type of problem-focused support based on legal issues emerged in the case of Beth, the former legal secretary, who reviewed a Will prepared by the ACLU for another ALS patient, "a little Mexican man." She said she "took the time to read it" and found some problems in the phrasing that could have created difficulties for property transference to the family. She called the person that prepared the Will and told him she would not notarize it until he adjusted the wording, and she said he sent a revised one to the family. These data are examples of problem-focused coping and support. The examples show that the skills that the volunteers obtain outside of hospice often become useful in performing their volunteer work, as well.

Relationship-focused coping appeared to be used frequently in finding ways to communicate and connect. A discussion of connections with the patients will be addressed in a separate section. Rene, the nursing student, found that the hospice team works together to create open communication about issues in a non-confrontational or non-blaming way. She said the nurses, social workers, chaplain, volunteers, and the entire hospice team talk with each other to make sure any problems are being addressed and resolved. The hospice team provides a good support network for any difficulties that may arise for volunteers.

Being present with the patient was another relationship-focused way to assist them in coping with illness and dying. Listening emerged as a common theme throughout the interviews. Sheila, Julie, and Yvette agreed that providing support to patients or caregivers should *not* involve using platitudes, such as comments like 'God's not going to give you more than you can handle' or 'Time will heal all wounds,' as these tend to minimize or discount painful feelings that people experience in dealing with death. Listening was more important to the respondents than having the right words to say. The volunteers frequently served as sounding boards for the fears and emotions that patients needed to express. Part of this included empathy, or acknowledgement and acceptance of all

feelings. Jan said it involves having an attitude of "That must be really a tough thing they're going through right now." Kate voiced a similar opinion in saying:

> As long as we go in there with the attitude that it's okay—wherever you are and
>
> whatever you're doing--this is normal and it's okay. Then the family settles down,
>
> eventually, and they finally come to grips with [it] as much as they're going to.
>
> But it helps them on the journey just to know that this is okay.

Sometimes, part of accepting patient feelings involves the volunteer participating in the grieving process. It appears to be a way for the volunteers to cope with their own feelings of loss, too. For example, Joan said:

> Oh, yeah, I cry *all* (word drawn out) the way home sometimes. (laughs) And
>
> sometimes I cry when I'm with the patient—cry with the patient. And so that's a
>
> coping skill. Yeah, sure we cry.

Rene, on her first experience of grieving with a patient, stated:

> And I just felt ... that was the first time—and I had had like 2 or 3 other patients
>
> before that—it was the first time that I really grieved with her, for her person.
>
> Just that painful, painful, world-changing realization that who you are and
>
> everything you know is going to change forever.

Crying can be considered an emotion-focused mode of coping but can also be considered relationship-focused, such as in the example given above, of grieving with the patient. Listening empathetically and grieving with the family can also be considered bereavement support, which is important in helping the family to cope.

The family caregiver often also needs support in coping with daily hassles, according to the respondents. Accepting the caregiver's feelings is an important part of support the volunteer provides. This includes allowing people the space they need to resolve their own issues. Jan was confronted with a conflict between father and daughter on how often to administer medication to

one dying woman. She said, "you have to be quiet. You have to leave them alone to let

them . [resolve their own issues]." In addressing the same family, she said she realized the husband

felt he was "losing control. Everything was going away. His whole world was leaving him, and

that was the little bit of control he had. So you kind of have to sit back..." In a sense, this was

giving him back some control by allowing him room to make his own decisions about what he felt

was best for his wife. Accepting the caregiver for where they are in the coping process and

allowing them to exert a certain amount of control, then, can be important, as well.

Appraisal of the situation, a key concept from the literature (i.e. Lazarus and Folkman, 1984)

emerged in the interviews, as well. Sally sees the volunteer's "energy," or how they approach the

situation and view the patient, as important. She indicated that the volunteer can provide a sense of

calm by seeing past the story line, and not viewing the patient as a victim who needs pity:

> I mean, it's just like not buying into or seeing the story of what's happening, but
>
> seeing them. .... And I think that's what a lot of volunteers can do. Once you've
>
> been around it enough, it's like you come in with this peace and a calm, and they
>
> feel it. You don't have to say anything; they feel it. And it's not, *Poor thing.*

Faith helps in the appraisal process also, and this is something that the volunteer can extend to

the patient, according to Kate. She noted that·

> If I'm calm and I'm confident and I'm reassuring--sometimes, my faith becomes
>
> their faith, and we don't even talk about it at all. If I'm confident that they're
>
> going to be okay and we get around these little issues of *Is there an afterlife?* And
>
> they've worked through an issue on their own and, if I'm sure that there is, there's
>
> that trust. My strength becomes their strength. My confidence becomes their
>
> confidence. And their fear seems to go away

Religion, faith, and spirituality are further addressed later in this section.

Acting as advocate for the patient and letting family dynamics resolve without interference was another type of relationship-focused strategy. Kate said that some families are dysfunctional, but that it is not the volunteer's job to fix them, but rather:

> It is our job to simply let the family dynamics work out however they're going to
>
> work out. We're the advocate for the patient, but we can't go and resolve 40 or
>
> 50 years' worth of melt-down in the family.

Sally noted that the volunteer plays an important role in supporting the family with coping:

> ...we do spend more time with the family and patient than any of the rest of the
>
> people who are coming... And you know the nurse is there is to check vitals and
>
> check on medication and pain, and the social worker comes in and talks.. so it's
>
> like having that whole big case load of... they have how many people per day...?

The volunteer is free to spend more time with the patient and family because they are volunteers and don't have the case load that nurses and social workers have.

Several earlier studies examined the importance of communication and help with decision-making as a means of support to families dealing with a dying loved one. For example, one study found that families were more satisfied when they were allowed to participate in communication and making decisions (Baker, et al., 2000). Good communication is important in hospice care so that the needs of the family and patient are properly being addressed and met (McGrath, et al., 1999). One respondent in the current study, Rebecca said rest and communication is a big part of coping:

> These people need rest. Get rested, and then communicate with one another.
>
> Don't, you know, go off and ... with your stress and start saying stuff that you're
>
> going to regret, you know. I mean, you're in it as a group. You know, when you
>
> have the family there, you know, ...We all have to work together. Not against

each other. It's inevitable that the loved one is going to pass away. They don't

need to have that tension in the home on top of it.

Volunteers provide respite care as one type of support that allows the primary caregiver the

opportunity to take a break and regroup. Joan also pointed out that volunteers must listen to

themselves and know when they are in need of a break, too. She talked about when she was feeling

worn out and unfulfilled:

> I thought, *Ah, listen to yourself and listen to your body and learn to cope with*
>
> *where you are right now and you need some time off--for whatever the reason is-*
>
> *-because when you're there, and you have to make yourself go, or you get*
>
> *through being there and you're really tired, and you just don't have that glow*
>
> *and that feeling, you need to be out.*

She trusted her intuition and indicated that she took a temporary break from volunteering.

So, coping can involve finding ways to help the patient cope and the family cope, and can also

include methods that the volunteer uses in their own personal coping.

Coping can be problem-focused, emotion-focused, or relationship-focused. Methods of coping

include cognitive and behavioral approaches. Appraisal plays a role in cognitive coping methods.

Effective coping usually involves the use of strong communication skills. Some coping involves the

use of religion and spirituality as part of the process. This will be addressed next.

Religion and spirituality in coping

In addition, spirituality and religion can be used in coping. Use of spirituality in coping was

common in the interviews. Respondents reported the use of religion, although more cautiously. I

will first briefly address the results for the final four questions on the participant survey (see

Appendix B), which relate to faith, religion, spirituality, and coping. The participant survey results

also show that most of the respondents used their faith in coping, and considered themselves to be

religious and spiritual, with generally more emphasis on spirituality than religiosity. In answer to

the survey question, "To what extent would you say that you are religious?" one said not at all, eight said somewhat, and six indicated they were very religious. More respondents indicated being very spiritual than did those reporting being very religious. In answer to the question "To what extent would you consider yourself to be a spiritual person?" three answered somewhat spiritual, and twelve answered very spiritual. The survey also included a question as to the degree of faith they had in a Higher Power that guides their lives. All 15 of the respondents said they always have faith in a Higher Power. The final participant survey question asked how often they use religion or spirituality in coping with stresses associated with doing hospice work. Four answered that they use religion or spirituality sometimes. Nine reported using religion or spirituality frequently in their coping. Two reported that they don't experience stresses with hospice volunteer work. Returning to the results of the focus group interviews themselves, the respondents reported using religious and spiritual coping methods that included prayer, singing faith songs, visualizations, reading from the Bible or other inspirational readings, sharing their beliefs and views when asked, and talking about God and spirit.

Rene felt that she brought her own spiritual foundation into the work, stating that:

I guess, I can't imagine the people get down-and-dirty right there, in what's happening, and not be able to have some sort of spiritual understanding of some sort. And so, I mean, when you talk about coping with your life and coping with hospice, there's just a certain amount of spiritual strength that you come to the work with, even before you start. And I think then once you're in it, you're praying. At least, I find that I do a lot of praying while you're with the person, you visualize what ... I like to visualize the light around the person.

She also indicated that she felt she had grown spiritually by working as a hospice volunteer, and that each experience:

> brings another understanding. And you get more and more levels…. Well, I mean
>
> you just learn more things. And so that helps you cope, which in turn helps you to
>
> do a better job.

Spirituality, therefore, seems to be an important resource used in coping, and spiritual growth and understanding can result from the coping process.

Jan, indicated "I know I am. I am definitely guided," saying she felt guided by a Presence when dealing with difficult situations. She shared what a hospice chaplain said to her when her own mother died:

> …and I don't think I'll ever forget it, he said, 'God is as close as He gets when a
>
> baby is born … when you come into this world and when you go out.' And I
>
> thought, "Wow, that's pretty … that's powerful.

The notion that there are divine beings present to guide and be there in difficult times was a comfort to many of the volunteers. It helped them to see the situation in a new way, coming from a spiritual perspective in which they felt less alone.

Joan shared:

> I have always felt like I'm a spiritual person, more than a religious person. And I
>
> find that a lot of people—family members and the patients too—can accept that.
>
> They can accept your being spiritual or them being spiritual, faster than they can
>
> accept the religious part.

She also addressed the importance of not forcing beliefs on people:

> Because it's really thin ice to tread on, unless you really get to know that patient,
>
> you know…to bring spirituality or religion into the picture. But, of course, it can
>
> be a big part of how *you* cope. Volunteer education is very strong. You're not
>
> there to save this person and convert them or whatever, but to help in any way that
>
> you can.

Dave, the retired Marine, revealed that working with hospice patients has brought him closer to his own spiritual life: "By giving my spiritual life to them, it helps me to understand it better, because I have to search my background, or my spiritual life, to convey to them." He sees the use of spirituality in coping as a reciprocal exchange. By helping others, it helps him also:

> So I think I've prepared myself better, in my spiritual life, by being with other
>
> people, helping other people to deal with theirs. And I think I'm a lot better
>
> prepared when my time comes than I had been, because of helping other people
>
> prepare for theirs.

Dave indicated sharing religious pamphlets or brochures with people, or sharing Bible verses with them. He also shares faith songs as a way of trying to inspire hope for those who feel hopeless. His overall perspective with regards to this type of sharing was:

> You know, don't try to evangelize. Just say where you're coming from. This is
>
> what you think, and maybe this might help you, too.… You know, I don't try to
>
> bring my faith into it, my denomination, here's what I believe. It's just overall
>
> general faith. I don't try and say, okay, Episcopal or Methodist, or whatever.

Ellen, a retiree from the third focus group, said she likes to know the religion of the patient and "I always ask them first if they are….what church they belong to." She also commented, "I always remind them that God is there just holding out His hand and helping them to make that first step up that ladder." References to God and faith as a source of comfort were frequently made.

Comparisons between religious tradition as opposed to a "real" spirituality arose in the interviews also. Sally, the massage therapist and breath worker, made a comparison between her past, in which she felt she was more traditionally religious, and more recent years in which her beliefs have become more real or true for her:

> Yeah, because I was raised Catholic, and I was such this little holy child, and you
>
> have no idea how many Our Fathers and Hail Mary's I did in my life. But it has
>
> been like the last 15 years that I finally really felt the words, you know, and that it
>
> was real and that it wasn't just words.

In other words, her faith has become a true resource for her, rather than something that is based only on ritual.

This group of volunteers, therefore, found a multitude of ways to cope and provide support, and indicated that they grew and changed in the process. The respondents learned more about themselves and what they could or could not cope with, and found that their spirituality played a large role in the coping process for them. Spirituality and religion served functions such as providing comfort, intimacy, and emotional release. The frequent application of spiritual coping by the volunteers in this study seems to support the findings of previous research by Pargament (1990), Stuckey (2001) and other researchers who found spirituality to have an important role in caregiver coping. Religion was also applied to the coping process. However, the respondents also had some ambivalence towards religion, often stating the importance of not imposing ones' denomination, values and beliefs on the families and their patients. Pargament (1990) and Jenkins (1995) found that there can be ambivalence towards religion, depending on the person and the circumstances with which they are dealing. An overall general faith seemed to be more acceptable to the respondents and the families they worked with. Merely sharing their own ideas and opinions when asked, and being there to listen and provide emotional support were support strategies commonly used by the respondents. Attributions to a loving God were also important in the coping process, as a way of finding meaning in dealing with death, which will be addressed further later in this chapter.

REWARDS AND REASONS FOR INVOLVEMENT IN HOSPICE

Caregiving can include numerous rewards. Picot and colleagues (1997), for example, found

reports of positive feelings and outcomes by some caregivers. These included avoidance of nursing

home placement and the opportunity to repay the care receiver for a past debt. The current study

found that the hospice volunteer participants also experienced rewards in providing support and

care for others. Several of the respondents discussed their reasons for becoming involved in hospice

and why they found it to be fulfilling. The reasons often were given within a spiritual framework,

in which the experiences were described as beautiful, transcendent and sacred. Hospice was

described as a spiritual calling or following one's path. Some of the respondents indicated it

changed them and their life perspectives, and said it was a gift to them as much as it involved them

giving to others. One person also described hospice volunteering as fun. Others indicated they had

confronted death themselves and wanted to help others in the transition to death.

The reward of sharing with others was an important theme. Sally, describing her first patient

experience at a facility that supported AIDS patients, said:

> My husband is usually.... The first time I came home from [name] House, It's
>
> like, 'So how was it?' 'I had so much fun tonight.' And it's like this is not what
>
> you think of with Hospice, but the people that work there, that's what it is. And
>
> it's an incredibly beautiful, life-affirming thing for me.

She elaborated that it is rewarding when the patients share with her things "that they might not

share with somebody else, if you'll just sit and listen."

Joan described her experience similarly:

> it was the greatest gift they ever gave me was the fact that they allowed me to be
>
> there to share that moment with them. And that's the way I always feel--when I'm
>
> with a patient that is close to dying or is dying—that they are sharing that
>
> extremely important part of their life with me and they're allowing me to be there.

Jan felt honored when a family phoned her as soon as their mother had passed. That they thought of her within minutes after their mother's passing felt good to her. Dave compared being present and holding someone's hand when they die to the "the most beautiful experience" of his life, which was delivering his youngest son. It was a gift to them to be present and share in the person's experience.

Spirituality and time transcendence were important themes, with death and hospice work described in a positive, life-affirming way by many of the volunteers. Death, just as birth, can be experienced positively according to Joan, who said:

> To be present at a birth is this wonderful, joyous occasion, and people cry and they celebrate, and the mothers, they'll have the whole family there now in the birthing rooms and everything. And…death is just that other, that other side…it's another transcendence of time. It can be a joyous time, too.

Rene described end-of-life care in spiritual terms also:

> …it's not sad, because at the end of a person's life, their essence is being boiled down to a very specific moment, and it's … you're in the presence of the transcendent of that time. And so just being there is such a… It's just being involved in something that is so sacred and holy.

She said that even with the most difficult personalities or challenging patients "The humanity of every person shines through. The authentic self comes out."

Several respondents spoke of the need to do something good, so that God would reward them for their good deeds, or to thank God for taking care of them. These data confirm the findings of Pargament and colleagues (1990), indicating that people perform "good deeds" as a way to ensure that they receive rewards from God in the future. For example, Joan offered the following explanation:

You build up all these good points. I keep telling my kids, 'I'm doing this hospice

work and I'm doing all this stuff.' And boy, you guys are going to take care of me

in the end,'…… I'm putting my time in now so that I've got somebody there at the

end.

Dave expressed gratitude, declaring "I come to hospice because the good Lord's been good to me, and I want to give some time back to other people. I enjoy helping other people." Jan indicated she was also giving back in gratitude for what she had received. Her first contact with hospice was when her own mother died, and she felt so much love from the people with the hospice agency, that she wanted to return the favor. She said, "They gave me something, and I still get something every time…I would not have wanted to do it without them." She added, "So hopefully, we can help them back the same way – make the end of somebody's life a little better." Gratitude for having received care and support from God and others, and the desire to perform good deeds, therefore, were reasons for performing hospice care, as well.

The respondents had more personal and situational reasons that prompted them to become interested in hospice work. Sometimes, the volunteers wanted to give the assistance they lacked receiving when they had loved ones that were dying. Yvette, a retiree from New Zealand, indicated that she was doing hospice work because she had difficulty dealing with her first husband's death from cancer, "and I looked after him, and when I came over here and heard about hospice, I had wished that I had that support when I was going through it." She said that family can't always help when coping with the difficult emotions, and hospice can fill that gap, adding "I realize now it's a privilege to be a caregiver for someone, to help them through these stages." Sheila lacked volunteer support when her father-in-law died, as the hospice agency in the west Texas town where they lived did not have a volunteer program. However, she said that they received a lot of support from the social worker, aides, nurses and other hospice workers, and described her experience with it as

"really a tremendous experience. So, I decided when it was my turn to do something, I wanted to do hospice." Beth felt she needed to fill a void in her life when her husband passed away, as she was "upset and I didn't have anybody to take care of.... And, so I decided, okay, I'm gonna do hospice. This was six weeks after my husband died." She went to the hospice agency and was told it was too soon after her husband's death to be a caregiver but that she could do office work. She felt that was fine, and so did office work and made cakes for people. She then eventually transitioned into direct patient involvement. Similarly, Ellen's involvement had to do with the personal losses she experienced. She had a 16-year-old grandson who she said:

"shot himself on purpose- he committed suicide. And we also lost a six-month old grandchild...if you've ever been to a funeral for a six-month old baby, you'd like to give something back."

She said the hospice group does "wonderful things, and they're always there for you. And I get a great deal out of being with people who need me, because I need them, too."

Julie indicated her reason for volunteering was that she "always had a need to volunteer...in something," and when she saw an article in her local newspaper, she became interested in hospice. Oscar also responded to a newspaper article about hospice volunteering, in another town he had lived in before retiring. Oscar voiced his appreciation for the hospice agency, indicating that he enjoys his relationship with the organization. He noted his gratitude for what he has received from his involvement, which is caring and support from the agency. For example, when his wife and he were both ill early in the year, he indicated, "I couldn't have asked for more compassionate consideration from the organization...they've solved a lot of my problems." Penny and Clint, the married retired couple, came to the hospice agency together. Penny reported that "I like to help people, and I take the most neglected....I don't have to hob-nob with the bigshots; that's not my bag. I go where I'm needed." She also commented that doing the hospice work was "All for God." Clint stated, "I lost my wife, and she (referring to Penny) lost her husband. We were neighbors, and...(pause) we got married (laughs). And she said she wanted to do hospice, so here we are."

She had always been involved in caregiving as a nurse and respiratory therapist, and he had served

as a medic in World War II.

Meeting people and hearing their stories were also reasons given for hospice volunteering.

Special feelings were associated with being there, providing comfort, listening to people, and

feeling appreciated. The experience of different cultures and history was also of interest to two of

the volunteers. Dave expressed it this way:

> And I love a lot of people...that's the main thing. Like, I met this gentleman that
>
> was born in 1918, that was raised around [a central Texas town] and he's telling
>
> me the history as he grew up. And it's a black gentleman, so he's coming from a
>
> different perspective. It's just interesting. A cowboy was telling me how a cowboy
>
> life was. You think of a cowboy as slinging guns, shooting at people...(laughs).
>
> That wasn't what a cowboy did. It's so interesting.

Rebecca shared similar sentiments:

> .... they have these stories, and they just want somebody to listen to them, and it is
>
> just so rewarding to listen to other lifestyles and to be there for them. It's very
>
> important for them to share that. So I feel honored when they do that....that they
>
> would trust me enough with that...it's very personal and you feel like you're
>
> connected after they share that with you.

Beth also experienced rewards with hearing patient stories. She mentioned one woman who had

lived through the depression era, with two small sons, and a mechanic husband. The family would

pick cotton together when the husband had no mechanical work to do. She admired that the woman

had worked so hard, and it was an inspiration to her to hear her stories. Dave described his

experience with one patient, indicating that the patient expressed gratitude that he was there to sit

beside him, hold his hand, and comfort him in his suffering. Dave noted,

"What causes us to do it is our faith, our love for humanity, our love for you at this time."

The interactions with others, loving them, and hearing about their lives felt very fulfilling for many of the volunteers.

Hospice also creates a shift in perspective that seems to be of a spiritual nature. Jan, the office manager, shared her thoughts on hospice work, saying, "I think it does make you get in touch with your own spirituality. You can't help it, when you deal with the end of life." According to Joan, the computer corporation employee, it allowed her to realize and focus on what was important to her. She said she was fed up with work one day, and the "petty stuff going on, and these rumors" and decided to leave saying she'd rather be holding somebody's hand while they're dying. She added, "This petty stuff isn't important you know. And it does help...Yeah, it does put everything in perspective for you." Rebecca feels that doing hospice volunteering puts her in a different mindset and helps her forget everything else when she does it: "It's like a different world. It's like your job, and whatever you do during the day, and your responsibilities are all cast away. It's a totally different mindset." Jan, expressing her view of the hospice experience said, "You know what it does doing this? It balances out the bullshit. The day-to-day, mundane crap of life... This is what's real over here." Hospice volunteering seemed to place their thoughts in a different realm, one of a more spiritual nature.

The respondents also referred to hospice volunteering as a ministry or calling, that they are spiritually guided towards doing. It is something that they say changes them and makes them grow. For example, Dave communicated that he felt he was "called to do it" and referred to hospice work as his "ministry." He also remarked that his personality had changed, saying that his personality growing up was entirely different, and that even ten years ago he would not have thought of himself as being the type of person to hold another's hand and pray with them. He noted that "something pushes me to go to do this, allows me to do it, you know." I asked him about his comment that his personality had changed, and he elaborated:

> Well, first of all, I've changed really ... my religious outlook has changed. But
>
> my whole outlook on life, I was trained as a ... you know, I spent 30 years as a
>
> Marine, trained as a killer. My whole job was as a sniper, to eliminate people.
>
> That was what my training was. And so you know, I ...[attitude was] 'You're
>
> nobody. Get out of my way.' So my whole personality has changed, and has
>
> changed for the better. I put value on people's lives.

He had faced death in his life several times, and realized "how critical life is" and how it is

important that people not die by themselves. Similarly, Rebecca referred to hospice as something

she was called to do. Rebecca said her reason for doing hospice was because she felt she was too

absorbed in her own life and busy being a mom. She remarked, "I just don't have a fulfilling life.

I'm just going through this mundane, one day after the other after the other." She felt the need to do

something "beneficial to humanity. And I realized that I needed to do what God put me here to do,

and that was to be a caregiver, to be compassionate, you know." She said she felt something was

missing in her life before hospice, commenting that she felt that "if somebody would just put their

arms around me and just hold me, that would make me feel so happy... when I'm giving the

attention, it's just like receiving it back." Both of these individuals felt that God had intended for

them to become hospice caregivers, and that they were acting based on that knowledge. Generally,

the respondents felt that the good experiences in doing hospice outweighed the bad and felt that

they were serving a higher purpose by being involved as hospice volunteers. The rewards they felt

they received in connecting with people were given as their major reasons for involvement and

commitment to staying.

The data reported in this section support the ideas from social exchange theory (Homans 1958),

which states that humans behave in such a way as to maximize rewards and minimize costs in

getting their needs satisfied. The exchange of goods that occurs in social behavior includes both

material and non-material goods. Non-material goods (or rewards) include gratification or social

approval. Other literature has built upon social exchange theory (for example, Kirschling, et al., 1990), noting that social relationships are sources of support and gratification, as well as being sources of conflict and costs. The hospice volunteers in the current study appeared to experience greater rewards than they did problems with this line of work. Wilson (2000) noted that volunteers weigh benefits and costs, but states that social exchange theory only provides a partial explanation for why people decide to volunteer. Volunteering is also based on social resources. For example, Wilson noted that those who attend church more frequently also volunteer more. Wilson's idea of volunteering based on resources could also apply to the current study. The respondents in this study, for example, reported coming into the work with a "spiritual foundation" that helps them cope. This spiritual foundation could be considered one resource. I did not ask the volunteers how often they attended church, but one of the survey questions regarded their self-perceived extent of spirituality. A majority of the respondents (12 out of 15) considered themselves to be highly spiritual, while degree of reported religiosity varied. Socioeconomic status can be another resource. None of the respondents in this study reported having money problems, and the level of income reported by two-thirds of them exceeded $35,000 a year. Another resource some of the respondents had was time, as almost half of the sample was retired individuals, who had extra time available to commit to volunteering. Skills, such as massage training, or past occupational experiences, such as in respiratory therapy or legal work, were also resources which were applied in their volunteer work. Reasons for hospice involvement, then, could include both availability of resources and rewards received from doing it.

CONNECTIONS OR TIES WITH PATIENTS

The respondents described many ways in which they built ties or connections with patients and families. These connections can be a major way of coping, as they provide social integration and a sense of belonging, both for the families receiving hospice care and for the volunteers. Hospice provides the connections that people dealing with the end of life need so that they feel less isolated

and alone. Hospice makes death a way of connecting with others rather than something to be hidden.

Small gifts were one way of creating a connection. Ellen, from the third focus group, gave angels to each patient, as her way of making a connection. The angels symbolized a source of comfort for her and some of her patients. Ellen expressed her thoughts about why she gave the angels as a gift: "the angel works for me. I always say that the angel is going to watch over them when I can't make it….It seems to have a meaning." She noted that one patient asked "if I would mind if they put the angel in the casket with them….it seems to mean a lot to the patient." Beth, also in the last group, called herself the "birthday cake lady" because she made and brought birthday cakes to whoever was having a birthday. She did this as her way of connecting with people and making them feel special. Beth had to let go of one patient (her first patient) when the woman's sister came to take care of her, and the sister did not want a volunteer there. Beth, to keep a connection with the patient, sent a weekly card: "Every Monday, I sent that lady a *Thinking of You* card…every Monday." She eventually created a bond with the sister when the sister called her to the woman's deathbed. Beth held her hand, listened to her stories, and stayed with her until Father Bob, the chaplain at that time, came. Beth added later on in the interview, that her training and experience as a hospital chaplain helped her to learn ways of connecting:

"I have found that when you walk in, and you take a hand, some people will draw back, and if they do, that's fine. But I always take a hand and just hold it." Kate, the insurance investigator/massage therapist from the first focus group used massage as a way to create a connection. She said she would even follow her patients if they move to a different facility:

> I stay with them all the way through the process. I won't leave….we just lost one
>
> of my ALS patients a few months ago, and she had two little dogs, and they got
>
> massaged every week when she got a massage (laughs).

Sally used her breath work and massage to connect. There were varied ways the respondents found to build trust and love with their patients.

Jan said that sometimes people don't request volunteers, but "if you can get a volunteer in the door once, they…get hooked." It involves making a connection, helping the family to feel comfortable with a stranger coming in, and the use of trust-building skills. Oscar reported, "You know, when you fill in like I do sometimes, and it's a one shot, you have to improvise. You have to really be alert to what they're wanting." He would go ahead of time sometimes just to introduce himself, and try to make the family feel more comfortable with him. Sometimes, an "ice breaker" was needed to help create a connection. For example, Dave mentioned working with an elderly black man, with whom he did not initially feel a connection. He said he felt rather uncomfortable at first, because the man was laying away from him, adding:

> So I went around the bed this way (indicating a direction) to talk to him, so he has .
>
> to look at me that way. As I went by, his foot was sticking out there, so I tickled
>
> him. It broke the ice…you have to smile if somebody tickles your foot. He just
>
> started loving at once…so we started talking.

The physical touch aspect was important to many the volunteers. Giving hugs, for example, was common. Jan said:

> Somebody told me when you give a hug- and I think this is true – make sure your
>
> hearts touch and you get a deep breath when you do it. I don't know how it does,
>
> but it melds your bodies together or something.

Jan mentioned her fear of being too attached to one particular patient she had "gotten so close to," and then having to face the fact that the family may not want her there when the patient passes:

> I have this thing … not everybody do I feel this way about, but this lady, when she
>
> gets sick like that, and she gets to the point where she's getting to the end, I want

to be there. And you have to be really careful with that, because the family might

not want you there.

However, she said she always feels committed, despite her fears. When "their friends quit coming" because they can't deal with the person dying, she said "Guess what. I'm not going to quit coming to see you." Their ties and commitments to patients were strong, according to several of the respondents. Jan said the ties are "much deeper" with hospice relationships, than in those relationships she develops outside of her hospice work. She compared the feeling of connection to a "real meditation," an experience of going deep within oneself.

Functionalist theory would predict that the connections that hospice volunteers create with patients and families serve the function of creating deep human bonds. These bonds are made with the intention of helping patients and their families make the "transition" more easily, with a sense of dignity and hope, and as free from pain and discomfort as possible. Religion and spirituality are sometimes used as gateways to supportive relationships, which serve the function of social integration (Ferraro and Koch , 1994). The current study shows that the volunteers used various methods, religious and nonreligious, to create connections and assist families and patients feel less isolated. The final section of this chapter explores how the respondents dealt with death, including past and present perceptions, talking about death and the afterlife, and finding meaning.

DEALING WITH DEATH AND FINDING MEANING

Phenomenological and symbolic interactionist thought have been addressed in other literature on caregiving (Glik, 1990; Park and Cohen, 1993; Parker-Oliver, 2000). Goffman's (1973) dramaturgical model has also been applied to hospice work by Parker-Oliver. Phenomenological thought, for example, is a subjective form of sociology, that states that reality is a social construction, that involves a subtle interchange of subjective meanings in everyday life. The interviews conducted in this study reflect the social construction of reality. The respondents expressed how they and the patients and families often perceived death fearfully initially. Through

interactions and the use of cognitive methods that involved reappraisal, and frequently involved the use of spirituality, some of them began to construct their notions of death in a new way.

Symbolic interactionism also can be used in explaining the findings in this study. Symbolic interactionism views the individual as an active and reflective social actor. In other words, our interactions involve thought and behavioral processes, wherein shared meanings are developed and communicated. These meanings can change over time as we learn to interpret events in our lives in new ways. Meanings influence our experiences, including how we perceive and deal with death. For example, the meaning of death to many of the respondents in this study, was often spoken of in spiritual terms. For instance, it was seen as a transition into another realm, a spirit realm. The beliefs, life experiences, and background factors, such as religious upbringing or length of time volunteering, influenced how they perceived death and dying. The hospice community itself brings its own ideas to the individual, as well. For example, the volunteer training usually includes specific instructions about proper behavior and attitudes in dealing with patients and families. The training includes instruction in not imposing one's beliefs on others, but rather being supportive, compassionate and accepting people for their own beliefs and feelings. The individual respondents applied their training and past experiences in interpreting events and how to cope with them. For example, several respondents reported accepting patients and families for whatever feelings they were going through, thus providing a safe space for them to process those feelings. At the same time, they framed death in spiritual terms; and this appeared to comfort the patients. The hospice community has its own shared meanings about death. The hospice community focuses on making the dying process as pain-free as possible. They don't try to hide death or stigmatize it but bring it out into the open (by placing the patient bed in the middle of the living room, for example). They also attempt to help the dying live their lives as fully as possible until they die. Symbolic interactionism, therefore, is pertinent to the understanding of the data in this study because of the shared meanings that occur within the hospice setting.

Finally, dramaturgy is a method that uses the theatrical metaphor, which includes the stage, actors, and audiences, in observing and analyzing everyday social interactions. The hospice team assists in the drama of dying and finding closure. It does so by providing comfort, companionship, and education about the dying process. The setting for this drama takes place usually in the patient or caregiver's home, and sometimes in a nursing home. Hospice acts as a resource, and the volunteers are one part of the resource team or the "actors" involved in the drama. The role of the volunteer is to be compassionate. They assist the family in the drama by being there to listen, providing physical care to the patient, and providing respite and bereavement support to the caregiver. They support the primary caregiver and patient in the transition into acceptance of the "dying role" for the patient. For example, they allow a space for processing of feelings of guilt and pain. They sometimes educate the family and patient about the stages they are going through. These may be emotional stages or the stages in the progression of disease, for example. They apply skills, such as massage, breath work, or listening, in performing their role. The "props" include hospital beds and various types of medications and medical equipment. This dramatic setting, the "actors", and the "props" all assist in the process of dealing with death and finding meaning.

Finding meaning in dealing with death was a major mode of coping for the respondents in this study. This involved discussing and trying to make sense of death and dying with the patients, and sometimes the patient's families. The participants in this study addressed how they talked with patients about death, their ideas about death and the afterlife, and how they perceived death as a result of working in hospice. They also exchanged views on societal perceptions of death over the last century, and how they feel that hospice has impacted upon those perceptions. Two respondents, Sally and Rene, both had near-death experiences, and they shared how that affected their perspectives, including not fearing death, as well. Initial experiences with the death of loved ones, before their involvement in hospice, were also addressed.

Yvette, most notably, indicated that death had not always been a beautiful thing to her:

I haven't had good experiences with dying. When my first husband had cancer, he

was in New Zealand. They called…the hospice was run by the Catholic nuns. And

they were wonderful to him. But they told me not to come, because they knew he

was going to die, and I didn't get called. So I wasn't there. When I walked in, and

as I went to the door, he was dying, and he was by himself. And he fought me all

the time, because he didn't want to die.

She said it made her frightened of dying. Her later involvement in hospice resulted from this

experience, as she wanted to help people go through the difficult stages of dealing with death. She

indicated that death still is not easy for her, but she is learning and growing by helping others. Beth

said one of the difficult issues for her in confronting death is her own emotionality, and fear of

crying too much around the patient. She wants to be there as a support, rather than crying. She

said, "I don't want to walk in and start grieving. I just don't want to do that to [the patient]." The

respondents sometimes had to face their feelings in isolation before feeling like they could be

around the patient. Ellen added:

I've had two patients ask if I know what it's like to die. How would you answer

that? Because I have [died]…they're me. I feel I have died a few times myself

from grief. So you talk to them about dying. It's nothing to be afraid of.

Talking with the patients about dying helped the respondents cope with and/or overcome their own

fears surrounding death.

Several of the volunteers commented that frequently patients will hold on, "waiting for

something" such as a reconciliation or dealing with an unresolved issue. Jan's comments were,

"They all terribly want their son to walk in the room and then they can go [or] they want to know if

somebody is okay, and then they'll go. I really, truly think people choose." This theme of needing

to resolve the past before they could go, or simply learning how to let go was prominent. An

example of this included Jan's story about a daughter who said the final lesson she learned from

her mother was how to let go of her. The daughter had an extremely difficult time, but the volunteer indicated she thought the mother needed to know it was okay to go. So, the daughter finally, after "having a really hard time," went into her mother's room, laid down beside her, and told her that it was okay to go.

Sometimes letting go involved discussions about what death would be like, and what would happen to them after they died. Telling them "what to expect and these are the stages, and you can stop- that this is like labor and delivery – in the early stages, you can slow things down" was a technique used by Kate, which helped to calm patients and give them a sense of control over the dying process. Talking the family and patients through the stages of death was mentioned rather frequently in the interviews. The volunteer training with most hospice agencies, in addition to their own experiences, teaches them about these stages and what to expect.

The respondents openly discussed notions of life in a different dimension, a spirit realm. As Dave phrased it, it involved "ending this part of your existence, but you're going to be existing somewhere else in a different plateau, a different dimension." Kate told one patient, that wanted to return the favor and give something to Kate in return for her caring, "When you get to the afterlife, you find my mother and give her a hug." Sally, in expressing her thoughts on an afterlife, indicated that when she died and came back, "mine was pretty pleasant, but I mean it's something like, that I *know*. It's not like I believe it; it's like I've *been there*." She said it affirmed for her that "life goes on, and that it [death] is just a change, and that people are around for me." Rene, the other volunteer who had been seriously ill, died, and then came back from death, said death was not scary for her anymore. It helped her to see strength in others, as they go through their dying process, what she called a "moment of incredible beauty and intimacy."

Jan said she thinks "people are going on to something much better [when they die]." She spoke of one current patient she had, stating:

> [He] thinks he might go to Hell. He's trying to figure that out…he keeps telling me
>
> all of the things he's done for his family, and then he'll tell me all the things he
>
> hasn't done [for them].

Jan indicated she has doubts as to whether she really believes in a Hell, and told him, in attempting

to console and comfort him, that everyone has done things that are bad, and that they regret, but

that doesn't mean they are a bad person. Most of the respondents believed more in a spiritual place

of comfort and peace in the afterlife rather than a physical place of punishment, such as Hell. The

notion of God as a loving, non-punishing being applied to many of the respondents' attitudes about

death and dying. In other words, people would find a place of peace and comfort when they die.

The focus on a loving, caring God validates the concept of attribution developed by Spilka and

colleagues (1983, 1985). Attribution theory states that we try to make sense of our experiences

and that we make attributions that cognitively explain events in such a way as to understand them.

Attributions to God and/or other spirits as a source of comfort in times of illness and death were

frequently used by the respondents in this study, as a way of coping. Those who indicated that they

looked to their spirituality or to God for support seemed to find more peace. If that is true, this

would appear to mirror the findings of Park and Cohen (1993), who indicated that those making

attributions to a purposeful, loving God in coping with death reported that they felt less distress

than those who did not.

Two of the volunteers in the second focus group, Rebecca and Jan, shared their beliefs that

there were spirits or entities in some of their patient's rooms when they were passing or at other

times, as well. Jan relayed the following:

> This is kind of weird, too, and you guys can tell me I'm nuts, if you want to. But I
>
> really think people kind of buzz by sometimes after they check out to let you
>
> know, 'Hey, I'm okay'.

Rebecca responded to that with "My brother did." Jan countered with:

My mother did that, too…I've taken a bunch of psychology courses. And they'll say, oh, yeah, that's because your mind is squirrelly right then, you know, and you're in a different space.….I do think you somewhat have to be open to it

Rebecca indicated she could feel the presence of something in the room:

…the hair on my arms would stand up, and I would feel this around me, and even the people in the room with me would acknowledge it.

She described walking into one patient's room:

and there was no one in there but her, and I went on the other side of the bed to fix her blanket, and I saw this dark shadow in the side of my peripheral vision. And I thought that the caregiver's husband had walked in the room, because I totally felt that it was a male presence. And then I turned around and there was nobody there, but I knew there was somebody there. And then another came in, and then another came in. And I felt this electricity around me, and it was like they were … it was her relatives. I just totally … you know, I just knew who they were, and I knew they were there to get her.

… It wasn't a scary or unpleasant experience whatsoever. It was totally peaceful.

With regards to talking about spirits or entities, Jan indicated it's comfortable to share that with other hospice volunteers, "but you can't talk about that in public." Basically, they had the sense that others would not believe them if they hadn't experienced the presence of spirits, as well. However, they did not seem overly concerned with what others think. They used these experiences to affirm in their own minds that life does go on, beyond the body.

Kate addressed more historical views of death, and noted that hospice recognizes death as simply part of the life cycle, not something to be frightened of or hidden away:

I think it's kind of fascinating because hospice actually is more of a reflection of a different time. Back in the '30s and '40s and '50s, we built hospitals… and we

made death something to be frightened of and to be hidden away from. And prior

to that, people typically died at home. And now we have made the full circle

again. And now we got to realizing this is simply part of the life-cycle.

Joan also commented that death could be viewed negatively or positively, stating,

"It [death] can be a joyous time, too. It depends on how people look at it...[we] now think it's a

failure, it's a failure when somebody dies." These notions of death as failure can be linked to

modern medical advances in overcoming many diseases, leading sometimes to unrealistic

expectations about conquering disease and death, so that when someone dies, the medical

institution feels like it has failed because they could not "save them."

Finding meaning in death helped the volunteers and the patients they worked with to face the

challenges with which they had to cope. From the respondents' perspective, the afterlife was

viewed as beautiful and peaceful, and as a good place to go when ones' life here on earth had

ended. Some of the respondents had viewed death more fearfully initially, and then through coping,

restructured their "definition of the situation" (Thomas, 1928) to see it differently. Some had

experienced losses in their own lives, and were able to apply these experiences to interactions in

their hospice work. By being able to view death differently, they were able to assist the patients in

the drama of dying, to find meaning and purpose in what was happening.

SUMMARY

The respondents discussed many ways of dealing with death and reported that they grew

emotionally and spiritually through the process of coping with the varied issues that arise in

hospice caregiving. Building connections, maintaining detachment when appropriate, sharing,

listening were some of the ways in which they coped with situations. The respondents experienced

some stressors, mainly related to dealing with more difficult diseases, such as ALS, or feeling

caught in the middle of unhealthy family dynamics. They often drew from their past experiences

with death, before entering hospice work, to assist them in supporting others. The volunteers

appeared to be a valuable resource for families and patients in helping them to make the transition through death. Rewards received in doing hospice work seemed to far outweigh the costs associated with it, and many seemed to be dedicated to remaining a volunteer for as long as they were able. Some of their experiences were couched in spiritual terms, while others were of a more worldly nature. The respondents indicated growing spiritually and learning what they could and could not cope with. Coping with death did seem to draw out the spiritual side of these individuals, and attributions to God were frequent and most often were positive attributions to a loving, comforting God. Symbols that related to spirituality included angels as a source of comfort. Finding meaning in death often occurred in a spiritual manner, as well, with reference to an afterlife and an existence beyond the physical body.

These findings are significant sociologically because they demonstrate how individuals behave within the hospice setting. The data provide a deeper understanding of the stresses faced by volunteers and the rewards that they experience in doing their work. These stresses and rewards may influence the level of dedication one feels in staying with hospice work. The meanings they share and the importance of these meanings to their own personal growth emerged through the study, as well. These meanings might also be relevant to how society at large comes to perceive death and dying in the future. If death is perceived fearfully and as something to be hidden away, more and more individuals may choose to institutionalize the dying in hospitals or other settings where they won't be seen. If death is perceived as a natural process, a part of the life cycle, as in hospice, dying and death might be a more positive experience for many. The findings also demonstrate how individuals apply cognitive and behavioral processes in helping them to reappraise death and dying. Spirituality emerged as a significant contributor in the coping processes used by the respondents. The role of God or other spirit beings was important to these hospice volunteers in creating shared meanings and making sense of their experiences.

The findings also reflect the important role that both men and women can play in acting as caregivers, as both genders in this study appeared to be equally nurturing and compassionate. In comparing the gendered experiences of the respondents, both the males and females in the study were open to new experiences in caregiving and seemed to enjoy their work. Feminist thought examines differences in experience based on gender. The males in this study appeared to be equally qualified for performing the duties of caregiving, including emotional and spiritual nurturing. Because the males appeared to be equally capable of emotional nurturing, this would provide a good argument for encouraging more males to become involved in the caregiving process. In fact, some male patients may prefer to have male caregivers.

Duration in caregiving was another demographic variable considered. The more experienced volunteers, who had spent a longer time volunteering, also appeared more comfortable with this work. The duration of caregiving finding reflects the importance of this particular background variable in hospice volunteering. Some respondents reported still experiencing stresses, but that they had learned to cope with them differently as they gained experience. Finally, the findings are important because they offer the opportunity for discovering new ways of improving end-of-life care. The concluding chapter will summarize these findings and address policy implications and potential areas for future research.

CHAPTER V

DISCUSSION AND CONCLUSIONS

This concluding chapter summarizes the key findings from this study, examines the strengths

and weaknesses of the study, and connects sociological and social-psychological theory with these

findings. Then, future directions for research and policy and practical implications are addressed in

the concluding remarks section of this chapter.

SUMMARY AND DISCUSSION

This study explored the experiences of hospice volunteers. The data from this study shows that

these volunteers felt very fulfilled in performing their work. They more often reported experiencing

rewards, and the stressors were often discounted as rather minor in comparison with the rewards.

The respondents often expressed feelings of joy, compassion, and gratitude. They were thankful for

how this line of work had helped them to grow emotionally and spiritually. When dealing with their

own stress, several noted the importance of listening to their intuition and knowing when to take a

break or maintain a certain amount of detachment. In assisting the patients and caregivers, spiritual

support was commonly used, including prayer, reading from the Bible, or singing songs of faith.

Other types of support included physical care, companionship, listening and talking with them, and

other types of emotional support, such as crying with the patient. Bereavement support and respite

care for the primary caregiver were also ways of providing support. Those who had special skills,

such as breath work or massage, put those skills to use in their volunteer work. Though death is

not always easy or beautiful, more often than not the volunteers indicated that they had

positive experiences. The human relations and interactions, hearing people's stories and sharing were particularly meaningful to them. They often used spirituality to reframe their appraisal of death or difficult situations encountered in performing their hospice work.

While the study identified several significant findings, it does have some limitations. Like most qualitative research, this study has a small, nonrandom sample; hence, the findings are not generalizable to all hospice volunteers. In addition, the sample was not racially diverse. All participants in this study were white, so no racial comparisons were available for this study. The sample included three males, but a more proportionate number of men and women would have made comparisons between men and women's experiences more accurate. The possibility also exists that a certain amount of self-selection into hospice volunteering occurs. In other words, individuals that tend to be more spiritually-focused in the first place may be drawn to becoming hospice volunteers more so than individuals with less spiritual focus.

Despite these limitations, there were several strengths of the project. The sample was diverse in terms of length of time spent in caregiving, which varied from less than a year to almost twenty years. This variation allowed for a comparison of experiences and coping skills based on length of service in hospice. Religious orientation varied somewhat, with most of the Protestant persuasion, and a few non-denominational or no preference individuals. Most importantly, the use of focus groups allowed the volunteers to discuss their experiences in-depth. Discussing sensitive issues with others who share a common experience allowed the respondents to explore and describe their everyday lives as caregivers.

The findings of this study provide support for various sociological theories. Functionalist theory was supported in that hospice serves the function of providing social integration and support for the dying and their families. Hospice allows these families to function as well as possible under the difficult circumstances surrounding death. Hospice also serves a religious or spiritual function for the volunteers, patients and families in terms of spiritual growth and learning how to cope.

Assisting in the transition from the "sick role" to the "dying role" is an important function of hospice. As Parker-Oliver (2000) stated, it helps them to redefine their lives and find new meaning in dying and death.

The data in this study also supported the ideas in social exchange theory (Wilson, 2000). The participants in this study often chose to volunteer because of the various rewards they experienced as a result of doing hospice work. They mentioned feeling that they received more from doing hospice than they felt they had given. The hospice volunteers seemed to appreciate the support they received from the hospice agencies, and felt that a reciprocal exchange occurred in the process of volunteering. The interpersonal relationships with patients, families, and other hospice staff were more often than not fulfilling to them. This finding is important for hospice agencies to consider in retention of volunteers. Provision of fulfilling relationships and support is likely to keep them active in volunteering.

Feminist theory could be applied to the findings as well, by comparing differences in gender experiences. Interestingly, the males and females seemed to have very similar experiences, and were equally open in expressing their fears and emotions. Perhaps doing hospice work helps all individuals in becoming more in touch with their emotional and spiritual side, regardless of gender. Hospice agencies might consider looking for ways to encourage males to become more involved in hospice, so that there will be more equal numbers of males and females involved in caregiving. Doing so could have implications for reduced differences in gender role expectations with regards to caregiving. It might lessen the burden upon females in our society as unpaid care providers, if more males and females become aware of the advantages of having both sexes involved in providing this care.

In addition to the insights of studying gendered experiences from a feminist perspective, phenomenology, symbolic interactionism, and the social construction of reality are reflected throughout the interviews conducted for this study. The individuals in this study, for example, used

their experiences in shaping and finding meaning in interaction with the terminally ill and their loved ones. They created new meanings for death that provided a sense of comfort and peace for themselves and the patients and families. Dramaturgy also plays a role in understanding the findings in this study. The interpretation of the social interactions that occur in hospice is primarily subjective, based on the views, experiences, and the backgrounds of the individuals involved. Background and contextual variables influence what they perceive. The hospice community acts as a resource for individuals, assisting them in interpreting what is happening to them and finding some sense of meaning in their life situation. The hospice team assists in the drama of dying and finding closure by providing comfort, companionship, and education about the dying process.

Finally, attribution theory is appropriate in explaining the hospice experience because it provides meaningful explanations for events and allows people to exercise cognitive control over processes and outcomes. In sum, attributions help in the coping process by assisting individuals in understanding what is happening in their lives. In the case of hospice and dying, attributions were frequently made to God. The events themselves are not as important as are the individual *appraisals* of them, according to attribution theorists. The findings of this study support Spilka and Schmidt's (1983) findings that stronger attributions to God occur with more serious circumstances rather than events of lesser significance. The respondents in the current study also made numerous references to God in speaking of death and the coping process associated with it. Hospice volunteers sometimes viewed death fearfully but had often overcome their fears of death and reframed death in more positive terms. For example, some viewed it as a beautiful experience, comparable to the birth of a child. Others referred to it as a transition into a different plane or an afterlife. They shared their perspective, when asked, with their dying patients in an attempt to provide some sense of understanding and comfort for them. Their own difficulties in dealing with death and loss also made the volunteers appropriate candidates to assist those who were

experiencing it while under hospice care. The volunteers' firsthand experiences of loss often helped them to be more empathetic and compassionate persons

The study confirms that stress and coping involve processes and attempts at dealing with life circumstances. The volunteers often felt uncertain about what to say or do at times, especially when they were newer volunteers who lacked experience in coping with specific situations, such as what to say about death when asked by a patient, or how to move the patient without hurting them. As they experienced more, they learned and grew, in competence to do the job and emotionally and spiritually, as well. Volunteering involved a process of facing challenges and learning what they could and could not deal with. It also involved learning when to take a break or when to stay out of a family confrontation. Finding ways to create connections were important in the process of coping. Numerous cognitive and behavioral methods were applied in coping. The types of coping used included emotion-focused (such as crying), problem-focused (such as helping the patient to breathe), and relationship-focused (which involved various communication and trust-building strategies). Hospice offers comfort and companionship to those in need of support when coping with dying. The continuing value of hospice will reveal itself as the population in the United States ages and further requires the assistance of hospice.

CONCLUSIONS

Much of the caregiver research in the last twenty years has focused on primary family caregivers, while some on paid caregivers has also been conducted. Research on the hospice community, especially volunteers in hospice, has been lacking. This study sought to fill that gap and examined the experiences of hospice volunteers. The voices of the 15 individuals in this study have allowed a further understanding of the stresses, the coping strategies, and the support systems they use The interviews explored how the participants used religion and spirituality, and the growth processes they underwent, in their work. These 15 individuals, both men and women, were found to be very nurturing and compassionate individuals. They had drawn on the sorrow, wisdom

and understanding gained from their own personal losses, in assisting others to do the same. Some had faced death head-on through their own near-death experiences and found death to not be as frightening as it would have been had they not gone through that.

Importantly, individuals from all three groups commented after the interviews had ended that the focus group was like a support group session for them and they appreciated being able to share and compare experiences with other volunteers. They indicated that group sharing is something they would like to do on a regular basis. The hospice agencies might wish to take this into consideration and perhaps arrange for regular support meetings between the volunteers, since they share a common purpose and can help one another.

This study suggests that future research could investigate elder abuse, as family abuse was mentioned a couple of times during the interviews. The research might include an investigation of reports by hospice volunteers and exploration of how often these reports receive follow-up through the hospice agency and other agencies providing adult protective services. Finding problem areas that may contribute to elder abuse could lead to educational opportunities and improved support systems to help reduce or prevent it from occurring as often.

Other potential areas for future research could include comparison studies that examine bereavement adjustment among those who have received hospice volunteer support as compared with those who have not. A qualitative study of this type could build upon the prior quantitative research of Ragow-O'Brien and colleagues (2000), who used questionnaires to study the impact of hospice on attitudes toward funerals and subsequent bereavement adjustment. A study consisting of family interviews could explore and expand upon this earlier research.

A comparison study of those receiving hospice care at home and those who receive it in nursing homes could be conducted to discover any differences that occur within these two differing environments. A couple of volunteers in the current study mentioned that the patients in nursing homes are sometimes angry with being displaced from their own homes, and this may affect the

quality of care received and experienced by patients and their families. A study of this type might examine ways in which the nursing home environment could become more amenable to the needs of patients and their families, and find problem areas that need policies directed at correcting them.

It might be beneficial to explore also what types of continuing education might be offered to volunteers and/or family caregivers that might assist them in coping with everyday stressors involved in caregiving. For example, dealing with such diseases as ALS can be quite challenging, and if the agencies could provide continuing support on how to deal with certain issues such as this, this could be of practical benefit in reducing health care costs and stress for caregivers. Perhaps this research will inspire further inquiry into the field of hospice that will produce answers to unexplored questions regarding elder abuse, continuing education for caregivers, and the future of hospice.

Future programs might also be directed at seeking ways of encouraging male participation in caregiver roles, as clearly it can be beneficial for men and women. The men and women in this study were very open and emotional about their experiences, and most indicated that they had grown from the experience and learned to be compassionate. Males and females should both be encouraged to take on nurturing roles, and hospice provides experiential learning in that regard.

Volunteers play a valuable role as part of the hospice team, and without them, a major gap in support and service to families would probably occur. The paid workers such as social workers and nurses are on tighter schedules, and must often rush from patient to patient, while the volunteers are on no set schedule, and can provide more relaxed support and nurturing. The study participants found their hospice work to be very rewarding, and they were very committed to it. Their continued commitment depends upon the hospice communities themselves finding ways to continue encouraging and supporting these valuable individuals.

APPENDICES

APPENDIX A

"Religious and Spiritual Coping Methods for Hospice Volunteer Caregivers"
Consent Form

You are invited to be in a research study of the experiences of hospice volunteer caregivers. The intent of the study is to learn more about the positive and negative experiences of and coping strategies used by hospice volunteers in their work with the dying and families of the dying. You were identified as a potential subject for the study through contact with your hospice volunteer coordinator, whom we asked to assist in recruiting interested volunteers for this study. The research will consist of a focus group interview of seven to eight hospice volunteer caregivers from the hospice agency. The research involves focus-group interviewing, in which the interviewer will ask questions, and allow the volunteers the opportunity to respond, as well as to guide the discussion in whatever direction they might like to go with the question. The interview is expected to last about one to two hours. This study is being conducted as part of a thesis research project for Masters degree student work at Southwest Texas State University in San Marcos, Texas.

You were selected as a possible participant because you are a hospice volunteer and have the necessary experience required to participate in this study. However, this does not mean that you must participate, as your involvement in this study is purely voluntary, and you may withdraw at any time. Please read this document and ask any questions you may have before agreeing to be in the study.

The purpose of this study is to explore the experience of hospice volunteer caregivers. This would include types of care provided, the rewards associated with caregiving, perceptions of dying, and assisting others in coping with the dying process. It will also explore stress, mental/emotional costs, and the coping process associated with volunteering as a hospice caregiver. The purpose is also to gain a deeper understanding of how religion and/or spirituality might play a role in the coping process for volunteers who care for the dying.

If you agree to be in this study, we will ask you to do the following things:

Come into it with an open mind, ready to share from your own experience, what it is like to be a hospice volunteer. You are expected to expend about an hour to two hours of time, if you choose to continue and remain for the entire interview. You may withdraw from participation at any time, if you choose to do so, without any type of penalty. You may also choose to not respond to certain questions, if they make you feel uncomfortable.

The entire interview will be recorded on audio tape, so that the information from this interview may be transcribed and analyzed for the purpose of this research. By signing the consent form, you are agreeing to the tape recording of your voice during the interview. You will also be asked to complete a brief

111

participant information form, that asks some questions about you, once you have completed the interview process.

The study has the following expected risks and benefits:

The study is expected to have no associated risks involved. No physical activity is required for participation in this study, so there is no risk of physical injury. The benefits associated with this research for you will be the opportunity to express how you feel about the hospice volunteer experience, and see how others in the same experience perceive and feel about it.

The benefits for the hospice agency (and perhaps other agencies) would be a possible increased awareness of volunteer perceptions and experiences, so that they might better serve their volunteers.

Your participation is voluntary, and all information provided by you is confidential. If the study produces any emotional or other discomfort for you, through discussion of the dying process and coping with it, you are free to withdraw at any time, if it becomes too uncomfortable for you to continue. We are providing a list of support groups, in case you should require assistance due to any emotional anxiety experienced in this discussion group.

All data collected from these interviews, including the audio tape recording, and all transcribed records of the interviews, will be kept confidential. All data will be made available only to the investigator, those assisting the investigator with this research project, as well as reviewers within the university system. The information from these interviews will be retained for approximately six months, while the investigator prepares the research report based on this study, and then will be destroyed and/or erased. Audio recordings, as well as transcribed records will only be accessible to me and my supervising professor.

The researcher conducting this study is Laura K. Hopingardner, Graduate Student, Southwest Texas State University. Her Supervising Faculty member is Dr. Patti A. Giuffre at Southwest Texas State University. If you have questions later, you may contact the researchers at:

Laura Hopingardner, 512-301-1619; lkhopingardner@juno.com or Dr. Patti Giuffre, 512-245-2113; pg07@swt.edu. You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

Signature_____ Date _____

Signature of Investigator _____Date _____

RELIGIOUS AND SPIRITUAL COPING METHODS FOR HOSPICE VOLUNTEER
CAREGIVERS – PARTICIPANT INFORMATION FORM

Please do not write your name anywhere on this form. This will help to ensure that your
information remains anonymous.
This information is being requested only for the purpose of this study and will not be released to
any unauthorized individuals.

1. Your sex:
   _____ Male
   _____ Female

2. Age: _____

3. With which one ethnicity do you most closely identify?
   _____ With no one ethnicity
   _____ Anglo American
   _____ Hispanic American
   _____ African American
   _____ Asian American
   _____ Native American
   _____ Other (please specify) _____

4. Marital Status:
   _____ Married
   _____ Divorced/Separated
   _____ Single

5. Highest Education level completed:
   _____ Less than High School
   _____ High School
   _____ Some College
   _____ College degree

6. Length of time you have been a hospice volunteer caregiver:
   _____ Less than 6 months
   _____ 6 months to 1 year
   _____ Between 1 to 5 years
   _____ Greater than 5 years

7. What is your yearly level of net income?
   _____ $ 0 - $ 14,999
   _____ $ 15,000 - $ 24,999
   _____ $ 25,000 - $ 34,999
   _____ $ 35,000 - $ 44,999
   _____ $ 45,000 and above

8. What is your religious preference? (please check only one)

_____ No preference

_____ Assembly of God

_____ Baptist

_____ Church of Christ

_____ Episcopalian

_____ Lutheran

_____ Methodist

_____ Presbyterian

_____ Other Protestant (please specify) _____

_____ Catholic

_____ Jewish

_____ Non-denominational

_____ Other (please specify)_____

9. To what extent would you say that you are religious?

_____ Not at all religious

_____ Somewhat religious

_____ Very religious

_____ Uncertain

10. To what extent would you consider yourself to be a spiritual person?

_____ Not at all spiritual

_____ Somewhat spiritual

_____ Very spiritual

_____ Uncertain

11. To what degree would you say you have a faith in a Higher Power that guides your life?

_____ I have no faith in a Higher Power

_____ I sometimes have faith in a Higher Power.

_____ I always have faith in a Higher Power.

_____ Uncertain

12. If you experience stresses with doing hospice volunteer work, how often do you use religion or spirituality to assist you in coping with the stresses?

_____ Never

_____ Sometimes

_____ Frequently

_____ Uncertain

_____ I do not experiences stresses with hospice volunteer work.

INTERVIEW SCHEDULE

I. Introductions
   Ask each volunteer to introduce themselves and state how long they have been a volunteer.
   Also, what drew them to becoming a hospice volunteer?

II. Questions:

1. What types of care do you provide as a volunteer caregiver?
   Probe: Ask for specific examples of emotional, physical, spiritual, mental care.

2. What do you consider your most stressful or difficult experience(s) as a hospice volunteer?
   Probe for problems or barriers: i.e. assisting with daily care activities; emotional issues;
   dealing with particularly challenging illnesses or patients or with stressed out family
   caregivers? Other?

3. What specifically was most helpful to you in coping with the experience(s)?
   Probe: Do you feel like you had a changed perspective or that the situation improved as a
   result of doing what you did? If so, explain or give an example.

4. How do you cope with and perceive the dying process? What role, if any, does religion and
   spirituality play in your coping and perceptions?
   Has your perception of death changed as a result of doing this line of volunteer work?

5. What is the most fulfilling part of hospice work for you?

6. Is there anything else that you would like to add to describe how you feel about your
   experience as a hospice volunteer?

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