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Good Grief! Coping with Death and Dying in a Hospice Situation

Pegg Warnick

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Good Grief! Coping with Death and Dying

In a Hospice Situation

(TITLE)

BY

Pegg Warnick

THESIS

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF

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CHARLESTON, ILLINOIS

1993
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Good grief! Coping with Death and Dying
In a Hospice Situation
Master Thesis
By
Pegg Warnick
Speech Communication
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Abstract

The purpose of this qualitative study is to discover and examine the coping strategies concerning death and dying from the perspectives of hospice patients and hospice volunteers. A review of applicable literature, informal but structured interviews and participant observation are procedures for the study. The focus of the study lies in three areas: what are the internal attributes used to cope?; what are the external support systems used to cope? and, what are the adjustments in personal goals? Research for this study was patterned after Hegge's study (1991) who surveyed the coping strategies of the recently widowed elderly. The instruments were changed only to better reflect the circumstances of the patients and volunteers. Patients and volunteers associated with Decatur Memorial Hospital's (DMH) Hospice were chosen for the study. Ten patients participated in the study. For each patient, a one-hour informal interview was conducted in the home. Telephone interviews, with a one-hour timeframe, were used for the volunteers. The study reveals that the key words for both patients and volunteers coping with death and dying are faith and acceptance. Faith was not only identified as a major coping strategy for both the patients and the volunteers facing the fact that the patient was dying, but was also used when patients and volunteers faced other major

crises in their lives. Acceptance, for patients, is two-pronged. The first acceptance is the acceptance of their own death. The second phase of acceptance is one of accepting the physical restrictions their diseases have imposed upon them. In volunteers, the acceptance of the death of their patients was understood. Those deaths appear to have no measurable effect on volunteers. For both patients and volunteers, faith and self-reliance were paramount in their acceptance of the situation. To develop a better understanding of how people cope with death and dying, this thesis will address the following research questions:

1. What are the coping strategies of the dying patient? Through what communicative forms does the patient discuss the grief and/or loss and other concerns of their illness?
2. How does the death of a hospice patient affect the hospice volunteer? Once a patient dies, what are the coping strategies of the hospice volunteer? Through what communicative forms does the hospice volunteer express those effects?
3. How does the hospice volunteer function as a liaison between the patient and the impending death of the patient? Through what communicative forms is the subject of death approached?

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Dedication

To Decatur Memorial Hospital's Hospice
patients, their families, hospice staff and volunteers:

Here's to you, here's to life!

Good grief!

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I wish to thank my thesis committee, Dr. Melanie McKee and Dr. Christine Helsel, for their support, encouragement and expertise.

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Thanks, too, to all the patients and volunteers who shared with me very intimate parts of their lives.

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Introduction

Talking about death is like a 10-year-old kissing his sister -- it is not an accepted practice. Even though death is one of the certainties of life, taxes being the other, we seldom discuss it in intimate terms.

No one escapes death, yet we do our best to avoid talking about it. In fact, avoidance is the number one choice of communicative strategies for Americans when confronted with the topics of death and dying (Kreps, 1988a). One reason Americans avoid talking about death and dying is because they are convinced that if a person knows he or she is dying, or accepts the impending death, he or she will lose all hope (Wentzel, 1981). For that reason, death and dying could easily be labeled the last taboo or the new obscenity.

This introspective, qualitative study focuses on three areas of concern in discussing the coping strategies of death and dying: the internal attributes and external support systems used to cope, and any changes or adjustments to personal goals.

While there is a plethora of research regarding various aspects of hospice situations, research is very limited when combining the coping strategies of death and dying in a hospice situation. Furthermore, research has yet to draw any comparisons between the coping strategies of the hospice

patient with the coping strategies of the hospice volunteer. Thus, this study will modify a study conducted by Hegge (1991) who surveyed the coping strategies of the recently widowed elderly. Hegge's instrument tool was modified to more accurately reflect the perspectives of hospice patients and volunteers. Responses from each of the two groups were then analyzed and compared.

Hospice patients and volunteers were chosen for this study because of the understanding that those associated with hospice have a greater tendency to discuss death and dying than those not associated with a hospice program. The reason for this often lies in the fact that hospice association requires that death be discussed.

Requirements for being enrolled as a hospice patient include: 1) The patient must be terminal. The disease must be so advanced that no further treatment will be administered. 2) The life expectancy of the patient is six months. Patients who survive longer than six months, however, are not withdrawn from the program, but are allowed to stay in it. 3) The patient must have a primary caregiver. A caregiver is the one who coordinates the patient's care 24 hours a day, every day. 4) The patient must be made aware of his/her impending death. 5) The patient must sign a form which states that no life support systems or resuscitation efforts should be attempted

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(Munley, 1983). Medical personnel are generally described as "curers", once a patient enrolls in a hospice program, however, medical personnel are referred to as "carers" (Wentzel, 1981, p. 8).

The hospice concept of care is not new. It is alleged to have been initiated during the Middle Ages, when hospice simply meant providing respite or a rest for weary travelers (Wentzel, 1981). Today's modern concept of hospice, revitalized in the late 1960's, is similar in that hospice provides relief for today's weary travelers of life (Davidson, 1985).

Review of literature

Dr. Cicely Saunders, credited with starting the modern day hospice movement, argues that talking about death is not morbid, but necessary in order to understand the process:

But to talk of accepting death when its approach has become inevitable is not mere resignation nor feeble submission on the part of the patient, nor is it defeatism or neglect on the part of the doctor. Our work then is to alter the character of this inevitable process so that it is not seen as a defeat of living but as a positive achievement in dying; an intensely individual achievement for the patient (du Boulay & Saunders, 1984).

Communicating with patients

The news media helps to perpetuate the mystery of death and dying. The portrayal of chronic illnesses by network television emphasizes treatment by drugs and/or technology. Interpersonal and psychological attempts are seldom made to deal with the illness (Turow & Coe, 1985). What few attempts are made at coping efforts translate into a few words of comfort or other short-term help, rather than plans for long-term handling of the problem (Turow & Coe, 1985).

The news media has become a channel for learning more

about disease, death and dying. A content analysis of select news media revealed that diseases such as cancer, heart disease and AIDS are thought of as moral objects, not just pathology (Clarke, 1992). Each of these diseases is portrayed differently.

Cancer is portrayed as negative, offering little hope for recovery. Heart disease is just the opposite. Since it only attacks one part of the body, the media portrays a higher recovery rate from a heart attack, a more optimistic outlook than cancer. The person stricken with AIDS is portrayed as a diseased person, hopelessly doomed (Clarke, 1992).

The news media is not the only source of information on disease, death and dying. Nearly two-fifths of all people seeking information about cancer receive the information from physicians (Johnson, Meischke, Grau, & Johnson, 1992). While there is an obvious link between communicating about death and dying and the health care professional, health care professionals seldom have the time, nor the inclination to talk therapeutically about death (Kreps, 1988a).

A survey of 600 members of the Academy of Hospice Physicians revealed that 97% of the respondents believed patients and families have a right to all relevant medical information that is available. However, 52% also believed that it is ethical for a doctor to withhold

information from a patient if they believe it will be harmful to the patient. If a patient does not appear to comprehend his/her terminal situation, despite receiving careful, detailed information, 90% of those surveyed would respect the patient's denial (Miller, 1991).

The importance of communication training for medical students and health care personnel is closely associated with the patient's satisfaction with their health care professionals. Poor communication skills by the doctor not only reduce the reliability of medical information, but also result in a reduction of satisfaction for the patient (Evans, Stanley, & Burrows, 1992).

Ideally, medical personnel need to learn to "read" a patient's nonverbal communication to assess the doctor's communication efforts. Physicians can then interpret a patient's characteristics to gain insight into how the patient might affect the doctor's plans for medical care. Patient cues that influence physicians' behavior include social cues, such as gender, age, ethnicity, race and socioeconomic status; physical cues, like physical condition and appearance; emotional cues, such as the emotions of discomfort, restlessness, embarrassment, anxiety, and/or fear in the patient's vocal intonation, posture, gestures; attitude cues, like vocabularies; and personality cues, such as a patient viewed as dependent, stoic or good natured

(Geist & Hardesty, 1990).

Patient cues are then used to determine whether to inform the patient, deny information and/or select a diagnosis or treatment option. Of the 100 patient cues associated with the three above-listed decision-making behaviors, 38 were associated with the decision to communicate information to the patient. Another 16 were associated with the decision to withhold information and 46 indicated a decision to select a diagnosis or treatment option (Geist & Hardesty, 1990).

When physicians do offer information to the patients, it is better received when the language is easy to understand. In a survey of 95 health care consumers, cognitive satisfaction, comprehension and recall scores were substantially lower in the technical conditions than in the nontechnical conditions. Also, the technical and nontechnical conditions did not affect the subjects' reported intent to comply or perception of the speaker's credibility. In addition, the amount of information received was not as important as the ability to understand it (Jackson, 1992).

In order to gain compliance with their patients, physicians resort to the use of expertise strategies, generally verbal communication. Under normal circumstances, they are reluctant to use force, threats or other verbally

aggressive communication strategies. However, those aggressive techniques are relied upon in the case of seeking compliance by patients who have potentially severe illnesses and histories of noncompliance (Burgoon, Parrott, Burgoon, Birk, Pfau, & Coker, 1990).

The patient's satisfaction with his/her doctor's communication immediacy behavior affects their reported satisfaction with the medical care they receive (Conlee, Olvera, & Vagim, 1991). In other words, if a patient is not satisfied with the attention s/he receives in the terms of attention, respect, medical competence, humility and accessibility, s/he perceives a negative relationship (Conlee, Olvera, & Vagim, 1991).

Perhaps one of the problems with physician communication skills is that prior to 1989 Medline, a computer on-line service for the medical industry, did not recognize "communication" as a legitimate term for its searches (Wyatt, 1991). "Communication" was a substitute for physician-patient relationships. Even then, articles on physician-patient relationships represented less than 1% of medical literature (Wyatt, 1991). While few articles did exist, one survey concluded that the time, place and manner of telling a patient about his/her cancer is important not only to the patient's understanding of the medical condition, but also to the patient-physician relationship

(Wyatt, 1991).

Patient communication with his/her physician plays a significant role in the provider-patient relationship. That communication offers more than just medical information to the relationship (Pettegrew & Turkat, 1986).

Patient satisfaction with physicians and a patient's communication behavior is strongly associated with the number of times patients visit their doctors. Assertive patients are more likely to visit their doctors than passive patients. Pettegrew & Turkat (1986) found in their research that the more a patient was an active communicator, the more the patient frequented the doctor's office.

Regardless of how active a communicator the patient is, generally communication between the physician and the patient is controlled by the physician. The doctor asks the questions, the patient responds (von Friederichs-Fitzwater, Callahan, Flynn, & Williams, 1991). By controlling the conversation, the doctor tends to change the subject more often, especially when emotional issues are raised by the patient.

One study suggests that the doctor's facilitating behaviors, such as encouraging patients to share expectations and concerns, were missing (von Friederichs-Fitzwater, Callahan, Flynn, & Williams, 1991).

A study on the Doctor-Patient Communication Inventory

(DPCI) revealed four significant communication factors for successful doctor-patient communication: relationship maintenance, professional competence, waiting time and social etiquette. (Schneider & Tucker, 1992).

Relationship maintenance includes small talk and nonverbal approachability. Professional competence simply means a concern with the doctor's ability to communicate a high level of proficiency in his/her medical practice. Waiting time involves the amount of time spent waiting to see the doctor. Social etiquette involves the doctor's use of language, dress and expressed self-confidence. Patients were offended by a doctor's use of foul language (Schneider & Tucker, 1992).

A healthy patient-physician relationship calls for relational health communication competence. This procedure requires both parties to possess communication knowledge and skills, such as empathy, non-judgmental listening, respect, message congruence and interaction management (Kreps, 1988b).

Physician-initiated communication may be characterized as either informational or affective in style. Although doctors believe patients should be given important information about their condition, often times patients possess only fragmented facts. Several explanations account for this discrepancy. One of those explanations is the

inability for a patient to ask questions when he or she is in pain.

Actually, communicating with patients about possible coping strategies has been found to be helpful in reducing postoperative pain (King, 1991). To help facilitate this accomplishment, physicians should be competent and open minded listeners, persuasive speakers, and conversationalists willing to devote time to the reduction of patients' uncertainties about procedures, painful sensations, therapeutic measures, and the like (King, 1991).

Communication not only helps reduce postoperative pain, but also assists reducing anxiety on the part of the patient. Cognitive approaches can also be used to effectively manage postoperative pain (King, 1991). The effects of communication and the role of the communicator can even go so far as to impact blood pressure and heart rates among patients in coronary care units (Garvin, Kennedy, Baker, & Polivka, 1992).

Communication is a powerful tool. A study was conducted by the National Cancer Institute on a group of patients who had been operated on for malignant melanoma. The operations were successful in removing the cancers. The study revealed that relapse did not tend to occur among those patients who confronted their illness with an active, positive approach. An active, positive approach involves

choice and information seeking. While these are the patients that physicians consider difficult because they ask questions and seek solutions, they are the very ones who tend to recover (Breitbart, 1990).

Enter hospice

The American hospice movement originated as an attempt to fill a perceived need or lack of personal care in the health care system for people with a terminal illness. Prospective hospice clients have a right to ask what kinds of benefits enrolling in a hospice program might bring them (Beresford, 1993). The strength of hospice lies in the unique and effective way that they meet the special needs of the dying and the bereaved, which are not met often within the existing healthcare network (Munley, 1983).

Hospice provides a quality of life, determined by the patient (Stoddard, 1978). The patient and his/her family are encouraged by hospice personnel to play the major role in life and death decisions (Wentzel, 1981). Hospice is not concerned with the treatment of the disease, but the needs of the person. The center of concern in the hospice program is the patient and his/her family (Wentzel, 1981). In other words, the focus is taken off of the disease and is moved to the patient.

The primary concern of hospice is to simply treat terminally ill patients as real people, living human beings, and not as people who are about to die (Wentzel, 1981). Communication between the patient, the patient's family and hospice staff about the illness and its implications are vital to the success of the hospice program.

Upon entering a hospice program, the patient and his/her family are made aware that there will be no further treatment of the disease. Once they are in the program, the only medical treatment is for pain relief.

Communication is direct, yet gentle. Patients, their families and loved ones, are encouraged to talk about their illness, their impending death and anything else that they want to discuss.

Hospice workers have discovered that the terminally ill patient has to work up to sharing their concerns. Initially, patients generally choose to discuss or share only the easiest issues for them to confront. Therefore, body language and what is not said takes on a deeper meaning (Selfridge, 1990).

While little is known about the decision processes to enter a hospice program, Gochman & Bonham (1990) completed a study on the social structure of such a decision. Questions were asked such as, Who makes the decision? What events led to such a decision? How informed are the decision-

makers about hospice?

Intensive interviews of caregivers, patients, physicians and others involved in the decision of 150 hospice cases revealed that the discussion was generally initiated to a professional outside the patient's household, that there were few who participated in the discussion, and that the patient's social network of family and friends was very important during this time of communication and decision.

The decision to enter the hospice program was likely to be made by the caregiver (Gochman & Bonham, 1990). A caregiver is defined as one who coordinates the care of the patient, and who is not a health care profession (Gochman & Bonham, 1990). Often times, the caregiver is a spouse or family member. The caregiver does not necessarily have to care for the patient, but just see that care is available at all times for the patient.

A study on the social structure of the hospice decision demonstrated the importance of the timing of communications about hospice. It revealed high levels of information about the hospice concept of health care. It also revealed that while the physician is the single most frequent source of information about the illness, social ties and networks played a pivotal role in the dissemination of information relevant to health care decisions (Gochman & Bonham, 1990).

Once a patient enters the hospice program, the focus shifts from the disease to the patient. Hospice represents a devoted effort to make inevitable death less distressing and more acceptable (Weisman, 1988). One of the ways hospice does this is to promote appropriate death. Appropriate death is defined as a death one might choose, if they had a choice (Weisman, 1988). Appropriate death has four characteristics: awareness, acceptance, propriety and timeliness.

A patient becomes aware of their impending death upon entering the hospice program, simply because they are made aware that no further treatments will be implemented, except to make the patient comfortable. That is the awareness factor.

Acceptance of the impending death sets in once the hospice patient has confronted any problems that need resolved. Acceptance of the unfairness of the terminal illness is the first step in being able to cope (Craig, 1991).

Propriety means being able to die similarly to the way in which one lived. This preserves dignity and relative autonomy because one is allowed to die his/her own death (Weisman, 1990). Timeliness is dying at the time of expectation or propriety. Some patients express a willingness to die (Weisman, 1990).

Two hospice nurses, Maggie Callahan and Patricia Kelley, report many of their patients experience nearing death awareness (NDA). NDA is an experience by a dying person who possesses a special knowledge or sometimes a control over the process of dying (Callahan & Kelley, 1992).

NDA differs from near-death experience in that those experiencing NDA remain in the body, but become aware of another dimension. Those having near-death experiences report leaving their bodies (Callahan & Kelley, 1992). Patients experiencing NDA often have such experiences over time and in a more gradual way. In other words, it is not just a one-time experience, but can occur several times. And they may have experiences with different people each time, or with the same people. They can usually talk during the experiences, enabling them to share these insights with others (Callahan & Kelley, 1992). Near-death experiences usually occur suddenly, in the course of a heart attack, while in the midst of a traffic accident or during a near-drowning.

There is much we have yet to learn and understand about Nearing Death Awareness. But, in ways that are direct or subtle, or even silent, dying people are (*italics*) showing us that they do (*italics*) know when their deaths will occur, and that they are not distressed by this information. By listening and understanding these

messages, we are given unique opportunities to prepare ourselves for their loss, and to deal with our fears of dying, to use well the time that is left, and to participate more significantly in this life event (Callahan & Kelley, 1992, p. 124).

As indicated in a study of the families of hospice patients at Hospice of Marin, California, the goal of the hospice staff is not to help families avoid crisis, but to help them manage in ways that respect their integrity and facilitate independent decision-making and growth. The success helping these families was found through structured and unstructured communication activities (Lillard & McFann, 1990).

When death is anticipated, the family's emotional functioning activities are thrown off-balance. During this time, emotional forces re-balance to compensate for the forthcoming loss. It is generally accepted that loss involves phases of grief and mourning (Schneider, 1984). However, people often do not realize that this reorganization of emotional forces within the family is covertly driven by how the family has traditionally reacted or responded in the past to crisis issues (Olson, 1988).

Hospice caregivers are usually family-focused. Hospice has long been associated with including the family in the

care of a terminally ill person. The family is viewed as the context in which the hospice patient lives and as the group of people most concerned with the patient's care (Hall & Kirschling, 1990).

When a family member is dying, families often find themselves in a dual position. They are a source of support to the dying member and they are in need of support as they experience the loss (Chekryn, 1989).

A study of 70 family members who were caring for a terminally ill relative enrolled in a hospice program concluded that support from family and friends is critical to the ability of caregivers to manage during the time of crisis (Kirschling, Tilden & Butterfield, 1990).

Hull (1990) identified three sources of stress faced by families caring for a terminally ill loved one: the patient's symptoms, interactions with others, and a concern for self. Concerns centered around the patient's decreased mental acuity, which meant normal interaction was no longer possible, and maintaining family roles and responsibilities among family, friends and personal care aides. Also, the concerns for self in reference to family members were identified: putting their lives on hold, personal health, lack of time for themselves, feelings of guilt, and isolation from family and friends (Hull, 1990).

A successful intervention in helping family members

cope with the stress brought on by caregiving duties has been a caregiver's support group. A study of the support group at Hospice Buffalo, Inc., revealed that the group offers a unique type of support that the hospice staff cannot provide, either through individual contacts or through family conferences. The reason for this: the special support is given and shared by family members in like situations (Bylewski, Beardi, O'Brien-McKenna, & Thomas, 1990).

Living with dying

Living with the knowledge of impending death is often overwhelming. Anticipatory grief describes the emotional experience of anticipating the death of a loved one (Lindemann, 1944).

The need for anticipatory grief begins when individuals begin to experience the physical, psychological or spiritual impact of the impending death. It is at the moment they first realize the illness is terminal that anticipatory grief can best be utilized (Huber & Gibson, 1990).

Rando (1984) argues that it is easier for families to accept reality before the death occurs than to try to cope with it afterward. She cautions, however, against assuming that people who have information will understand it, react to it, or actually begin grieving prior to the death.

Rando (1986) also argues that anticipatory grief is experienced by the dying patient, as well as by those emotionally involved with the patient.

Levy (1991) discovered that anticipatory grief is more dependent on the individual's level of emotional adjustment and ability to cope with stress and crisis, than on any other factor.

Huber & Gibson (1990) surveyed 134 bereaved survivors, 20 months following the death of their loved ones. The study included a new tool called the 10-Mile Mourning Bridge, which was a hypothetical 10-mile bridge representing the grief process. The journey started at "0" miles, where the bereaved first gained knowledge of the impending death of their loved one. The journey ended at the 10-mile-marker, which represented the place where the individual is able to re-invest emotional energy and get on with his/her life (Worden, 1982).

Participants were asked to visualize the grieving process as a 10-mile mourning bridge that had to be successfully crossed before they resumed their lives. The first question ("How much of the bridge had you already crossed by the time your loved one died due to hospice care?") had an average response of 4.6 miles across the 10-mile bridge. In other words, nearly half of their grieving had been accomplished through the efforts of the hospice

team and concept of care by the time of their loved one's death (Huber & Gibson, 1990). At the time of the interview, 20 months after the loved one's death, survey respondents reported they were about 8.3 miles along the bridge. The responses varied for surviving spouses. They reported that at the time of death, surviving husbands were 4.4 miles, while surviving wives were at the 4.7 mile marker. Twenty months later, surviving husbands were 8.4 miles along the bridge, with surviving wives right behind at 8.3 miles. This study concluded that intervention and communication by the hospice staff contributed to the survivors being able to cross the bridge prior to the actual death (Huber & Gibson, 1990).

Religion and spiritual well-being play a significant role in enabling caregivers, patients and hospice volunteers to more effectively cope with death and dying (Koenig, 1988; Kirschling & Pittman, 1989; "Coping with Grief," 1983). A study by the Missouri State Division of Aging found that persons using religious beliefs and prayer during stressful situations were significantly more likely to report low or no fear of death (Koenig, 1988).

Robbins (1991) surveyed hospice volunteers on their concepts of death anxiety, death competency and self-actualization. What she discovered was that studying death competency or coping with death may be more useful than

studying death anxiety to understand people's emerging self-actualization in the process of confronting mortality.

Ann Wade, a mother whose young daughter died unexpectedly shouted to her friends: "Don't take my grief away from me. I deserve it, and I am going to have it (Manning, 1985)." Manning (1985) compares grief to a bump on a leg: "We see the result of the bump, a bruise. But we do not see the action that caused it or the cause." So it is with grief.

Twenty-six newly widowed elderly were interviewed about their grief (Hegge, 1991). These interviews revealed the most frequent and troubling problems among surviving spouses: loneliness, social isolation, disruption in eating and sleeping patterns, and independent decision making (Hegge, 1991). It also identified that faith, energy and stamina were the internal attributes used to cope with the death of a loved one, and that their children provided the main external support system for coping (Hegge, 1991).

Interviewed 13 months after the death of a loved one, 97 bereaved survivors reported that they were managing their lives and coping with their loss without undue stress (Longman, Lindstrom, & Clark, 1989). What the respondents reported was that 58% were more lonely; 23% more depressed; 24% more anxious and 23% more fearful. Although these feelings were expressed, 45% of them believed they were

experiencing some recovery.

Participants in a bereavement support group indicated that they received both short- and long-term benefits from their involvement with the support group. Their participation increased their ability to cope. As a result, the support group became a vital part of their external support system. The benefits received included increased emotional, mental and physical stability during and after their participation (Rognlie, 1989). One of the major focuses of the support group was to allow participants to express their feelings and discuss their experiences. Of those surveyed, 80% agreed that the communication factor within the group was most helpful.

Coping with death and grief involves creative, emotional and skilled care. Sometimes coping takes on communication forms other than verbal. Through adopting coping strategies, the terminally ill patient and their loved ones can develop emotional, social and spiritual wellness.

Dying can be defined in terms of first, second and third person. Third person dying is talked about in abstract terms, such as when teaching about death. Death in the first person is one's own death. Death in the second person requires identification with the dying person and is seen in relation to death of loved ones (McEvoy, 1990). As

there are terms with death, there are stages to mourning.

There are four stages to mourning: accepting the reality of the loss; experiencing the pain of grief; adjusting to an environment without the deceased; and withdrawing emotional energy and investing it in another (Worden, 1982).

Dush (1988) discovered that volunteers or paraprofessionals are often utilized to counsel the bereaved. He suggests that these volunteers must be viewed by others as well as themselves, as helpers and not as friends, when providing bereavement support.

Coping mechanisms that work for surviving caregivers can be implemented for the dying patient, as well. Before the patient can die, s/he must come to an agreement about the death. Coping with the impending death is one of those steps (Stoddard, 1978).

Wholihan (1992) conducted an experimental study on hospice patients to determine the extent of self-esteem disturbance and to assess the efficacy of a guided reminiscence intervention program. Fifty-five percent of those tested were found to suffer from self-esteem disturbance. Yet patients who engaged in guided reminiscence showed 16 times more improvement in self-esteem scores as compared to those patients engaged in social conversation. Guided reminiscence encourages patients to

reminisce and review their lives, specifically to "point at their contributions and suggestions" (Wholihan, 1992, p. 34).

Music also can be utilized to help patients and their loved ones cope with the process of dying. Brown (1992) found that terminally ill patients often relieve pain and their fears by singing. Patients who can deflect their thoughts, through music or other sources, often are relieved of their pain for a while.

Art therapy has been introduced into many hospice programs to help patients and their loved ones express their fears, their grief and their concerns. The arts help to identify therapeutic issues and provide a means to work through the issues (McIntyre, 1988).

Humor provides an invaluable tool into coping with stress and crises. Even the Scriptures admonish us: "A merry heart does good like a medicine, but a broken spirit dries the bones" (Proverbs 17:22). Zimmerman (1986) maintains that humor is a vital part of life. "Terminal care is no exception. The gentle and appropriate use of humor can do things no other therapy can provide. Its value must not be overlooked" (Zimmerman, 1986, p. 36).

Research exploring the functions of humor uncovered three major factors: positive affect, expressiveness and negative affect (Graham, Papa, &

Brooks, 1992). Another way to label them is laughing with (positive), laughing at (negative) and laughing (expressive). The positive affect offers inclusion, that is, humor helps people identify with one another. Negative affective humor is viewed as a form of control -- putting one in one's place. Expressive motives, or self-disclosure, is a form of showing affection to one another.

"When we laugh at someone we exclude the person from the network of love, understanding and support. But laughing with allows us to enfold or include the individual with it" (Moody, 1978, p. 109). Moody argues that telling a terminally ill person a joke or getting the patient to laugh is good, but that helping them adopt a humorous perspective to life is even better.

Herth (1990) also uncovered three functions of humor -- physiological, psychological and sociological. In her survey of terminally ill patients, 57% identified humor as a significant part of their life prior to their illness. While 85% indicated that humor would be helpful at that particular time in their lives, only 14% admitted its presence. Humor was described as empowering hope in 85% and more than 60% of the participants believed humor enabled them to alter their perceptions of situations that would otherwise be overwhelming.

The medical profession is slowly starting to take the

value of laughter seriously. Oncologists at Duke University Hospital offer a "laughmobile" cart stocked with funny books, videos, games and monologues by such humorists as Bill Cosby and Erma Bombeck. At the University of Michigan Hospitals in Ann Arbor, Consultant Lila Green conducts humor workshops for health care workers to reduce stress and prevent burnout (Gallo, 1989, p. 32).

Author Norman Cousins startled the health care profession when he announced that laughter was a healing force for his illness. Told that he had a serious illness, he checked himself into a local hotel and watched videos of the Marx Brothers and Candid Camera to relief his pain. The laughter provided a two-hour respite from the pain (Cousins, 1979, p. 40).

Cousins also maintains that pain relief is not the only benefit from laughter. Researchers have also discovered a wide array of changes brought about by laughter, from enhanced respiration to increased immune-cell activity (Cousins, 1989, p. 96). Bailey (1988) discovered that laughter puts problems into perspective, improves our health and keeps us in touch with one another.

One of the best uses of humor for the terminally ill person and his/her family is as a coping mechanism. If humor does promote good mental health, it does so by allowing us to cope with sources of conflict and stress

(McGhee, 1979). Humor promotes creativity and an exhilarating sense of discovery that makes this time of anxiety and uncertainty a little easier to handle (Rovinski, 1990, p. 220).

No one can argue that facing one's death is easy. Communication of fears, regrets, hopes for the future and other concerns are necessary to make that confrontation easier. Communication competence for patients, their families and loved ones, as well as the hospice interdisciplinary team and other medical professionals, is vital to alleviating the taboos and mystery of death and dying (Sharf, 1993, p. 39).

Method

In order to determine the coping strategies of the terminally ill, subjects for this qualitative study were hospice patients and hospice volunteers. Good coping is a product of flexibility, resourcefulness, pragmatism and optimism (Weisman, 1988).

Qualitative procedures are judged by these criteria: informational adequacy, efficiency and ethical considerations (Marshall & Rossman, 1989). An informal interview format, with its casual conversation combined with structured questions, was developed to meet the above-listed criteria.

Qualitative study has at least two elements to it: social relations and data collection. Social relations means gaining access to the group being studied and then, once there, maintaining confidentiality, making a proper exit and at all times, conducting the interview in an ethical manner.

Data collection involves collecting the raw data and then determining what facts are relevant, recording data, developing constructs and structuring reports (McKee, 1990).

Designed as a qualitative survey, this study of patients and volunteers used a structured interview tool that focused on three important factors: internal attributes used to cope, external support systems used to

cope, and adjustments in personal goals. The research tools were similar to an instrument developed by Hegge (1991) on coping strategies.

In that study, she examined the coping strategies of newly widowed elderly. The focus was on the effects of anticipatory grieving before the spouse's death (Hegge, 1991).

Anticipatory grieving is the emotional experience of anticipating the death of a loved one (Lindemann, 1944). Loneliness, social isolation, disruption in eating and sleeping patterns, and independent decision making were found to be the most frequent and troubling problems among surviving spouses (Hegge, 1991). Hegge also discovered that faith, energy and stamina were the internal coping mechanisms, while those surveyed admitted that their children were their primary external support system. As for any changes or adjustments in their personal goals, several said they made none, while others stated that they intended to travel, move to a retirement village, or just take one day at a time. Three of the 26 surveyed stated that any personal goals they had died with their spouses (Hegge, 1991).

Subjects

Persons associated with the Decatur Memorial Hospital

(DMH) Hospice were the chosen for this original research. Hospice patients and volunteers were selected because of some of the requirements in order to be enrolled in a hospice program. The main ones, in regards to this study, include that the patient is terminally ill with no hope for recovery, a life expectancy of no more than six months and the patient must be aware of the prognosis and life expectancy (Davidson, 1985).

In other words, the patient is told that there will no longer be any treatment of the disease, that the disease is so advanced that nothing further can be done to combat it. The patient, possibly for the first time, confronts his/her own mortality, head-on.

In the same manner, hospice volunteers are trained to cope with death, exposed to anticipatory grief and bereavement counseling.

Patients and volunteers were chosen from Decatur Memorial Hospital's (DMH) Hospice program. The patient care coordinator at DMH Hospice supplied a list of patients who expressed interest in participating in the study. In addition, a hospice nurse supplied the name of another interested patient.

Before releasing the names of the patient, the DMH Hospice patient care coordinator personally contacted each patient by telephone and asked if he/she would be interested

in the study. Initially, a list of 12 patients was compiled. However, before the list was completed, the conditions of two of the patients had deteriorated to the extent that they were too weak to communicate.

As a result, 10 patients participated in the study. Before all interviews were completed, the two patients removed from the study died.

Informal interviews were conducted in the homes of each of the patients. According to Fetterman (1989) informal interviews, while they often reflect casual conversations, have a specific, yet implicit research agenda. The interview format was used to discover any commonly held beliefs, values, coping strategies and communication efforts of hospice patients.

A questionnaire of 19 questions was developed (see Appendix A). Of the 19 questions for the DMH Hospice patients, four of the questions were closed-ended; the remaining 15 were open-ended questions. A closed-ended question was used to help to quantify behavior patterns. An open-ended question allowed participants to interpret it (Fetterman, 1989).

Interviews were scheduled in the homes of each of the patients during the weeks of October 24 and 31, 1993. Each patient was instructed that if there were any questions that made them uncomfortable, or that they did not want to

answer, their request would be honored. None of the patients refused to answer any questions. A one-hour timeframe was allowed for each interview.

A similar study was conducted with volunteers at DMH Hospice. The volunteer coordinator supplied a list of 12 hospice volunteers to interview. None of the volunteers were contacted prior to the interview. Also, none of the volunteers chosen for the study were volunteers for any of the patients participating in the study.

The volunteers were interviewed by telephone during the weekend of November 6, 1993. Eleven of the 12 were interviewed. One of the women interviewed represented a husband/wife volunteer team. Only her responses were recorded, since her husband was not available for an interview.

For the volunteers, a questionnaire similar to that of the patient's was utilized (see Appendix B). Of the 22 questions, five were closed-ended; 17 were open-ended questions. Again, each of the respondents were told that they could refrain from any questions that made them uncomfortable. None did.

Gaining Entry and Social Acceptance

Social relations plays an important part when conducting qualitative research (McKee, 1990). Being

accepted by those being interviewed makes for a much more relaxing and more credible experience.

To better understand the hospice concept of healthcare and because I wanted to become more involved with the hospice program, I completed a 20-hour volunteer training course six months prior to conducting the interviews, becoming a certified hospice volunteer. In addition, a five-week course, "Growing through Grief" was completed.

Two years earlier, I had been a caregiver for my Mother, a hospice patient. She died five months after entering the program.

To gain entry into a patient's life, the hospice patient care coordinator explained the study and introduced me, not only as a volunteer, but as one who had been a hospice caregiver for a relative.

For entry into the volunteer's world, I introduced myself as a hospice volunteer and explained the survey. Some of the volunteers received their training the same time I did, so we were already acquainted. One volunteer was already aware of the study because a patient who had participated in it, told her about it. Gaining acceptance into the hospice community of patients and volunteers was not a problem for me. In the eyes of many of those I interviewed, I had earned my way into their intimate setting because of my experiences, and as such, I was already a part

of it. I had a genuine interest in the lives of each of the people I interviewed and because of my experience as a caregiver and a volunteer, I could easily identify with what they were experiencing.

I am confident my subjects were convinced of my sincere interest in the program and my empathy for each of their lives. As a result, the patients and volunteers opened up to me the most intimate part of their lives -- their perspectives and their insights on, and even their very own experiences of, dying. Not only that, but they wanted their names used, if at all possible. I was given permission to use both first and last names, and to release any information we discussed.

Data collection

Before I conducted any fieldwork, I acquainted myself with readily available information on hospice, as well as completing the aforementioned training. Comfortable with the knowledge of the written work on hospice and armed with my volunteer certification, branching out into the field to conduct interviews seemed very familiar ground to me. Six months after I started my information journey, I sojourned into the lives of hospice patients and volunteers, eager for their insight into coping with the knowledge of their impending death.

Stoddart (1986) outlined four criteria necessary for ethnographic adequacy: ethnocentrism, methodogenesis, presence and credibility of informants. Ethnocentrism concerns the validity of the research. It determines if the data is genuine, or if it is something concocted by the researcher.

To establish validity, hospice patients were given the draft of this research to review. The similarity of observations within a specified timeframe provided reliability.

Methodogenesis examines the adequacy of methods. Were methods discovered or domains created? To ensure discovery, the subject was allowed to volunteer information.

Presence refers to the reactions of subjects to the researcher. While my hospice experience allowed me access to the subject's lives, I also became something of an invisible researcher. Even though I always stated that I was conducting research, sometimes they seemed to forget and instead, they would include me in conversations that would normally take place between good friends.

The credibility of informants questions how reliable the subjects are (McKee, 1990). It was important that I have subjects representative of the hospice community, and ones well informed of their situation. I believe that was reflected with both the patients and the volunteers.

Results

The range of time for patients in this survey, at the time interviews were conducted, ranged from one week to 18 months, with the average time being just under five months. Jill, at age 30, was the youngest interviewed. Other ages ranged from 60 to 80 years of age; the average age being 68. Of the 10 patients, six were female, four were male.

The amount of time spent as a hospice volunteer ranged from seven months to six years, while the average was three years. Julie has only had one patient to date, yet Mary and Bob, the husband-wife volunteer team were responsible for 12 patients. Overall, there was an average of seven patients. Of the 11 volunteers interviewed, nearly every volunteer admitted they were not sure of how many patients they had been assigned to, but they were able to remember their names and some associations with them.

Internal Attributes.

Findings of the qualitative study of coping strategies of patients center around two words: faith and acceptance. Nine of the 10 patients agreed that they had accepted the fact that they are dying.

Insert Table 1 here

Faith and/or self-reliance were identified as the coping mechanism most employed when dealing with the realization of his or her terminal illness, as well as when the patient had faced other major crises in his/her life. Seven of the 10 patients interviewed admitted that faith played a major role in their lives.

For volunteers, acceptance of the patient's death was not a problem. The deaths of their patients has had little if any effect on lives of the volunteers. Only Emma expressed concern over a death. She admitted to experiencing a deep loss when her patient, a 102-year-old woman she had been associated with for 18 months, died. Emma and her patient played Scrabble every week for 1 1/2 years.

Of the 11 volunteers surveyed, four said they had close relationships with their patients, and another group of four said they had good relationships with their patients. Heather, Leon and Gigi each said their relationships varied with each patient.

Insert Table 2 about here

"Faith has played a big role in my life. Even though I was raised in the church, it didn't really sink in until I became ill. I sometimes wonder if the reason I got sick

wasn't to get me right with God (J. Jordan, personal communication, October 24, 1993).

Phyllis admitted that faith was a major coping factor for her, too. "I was always too busy for God. But now that I spend all of my days and nights in bed, unable to go anywhere or do anything on my own, I've had plenty of time to talk to Him. I know I need Him (P. Roberts, personal communication, October 29, 1993). Only Marian said that she relied on "guts" to deal with any major problems in her life (M. Miller, personal communication, November 2, 1993).

Acceptance for patients is two-pronged. Once they accept their impending death, they must then work to accept the physical restrictions their disease has imposed upon them. Because of their illness, they can no longer do what they used to and they are having to resign themselves to accept that some things may not get done.

The response from the volunteers mirrored those of the patients when discussing internal attributes used to cope. Of the 11 interviewed, faith and acceptance tied as the top answers for strengths used to cope in a hospice situation. However, "don't know" was a top contender, too.

"I have grown stronger in my faith (since becoming a hospice volunteer). Even though I have not had patients of the same faith I am, I pray for them and their families (G. Langhauser, personal communication, November 6, 1993).

Echoed Esther: "I don't think I could have stuck to it (hospice) without my faith (E. Reynolds, personal communication, November 6, 1993)."

Volunteers also credited listening as a coping tool. When discussing other major crises in their lives, one volunteer admitted she had not experienced any real crises, and a second volunteer stated that she did not perceive hospice as a crisis.

While the patients were equally divided in that five of the patients identified the disease as being sudden and five stated it was slow to progress, four of the six females said the disease was sudden. The opposite was true with the men -- three of the four men responded that the disease was not sudden, but slow to progress.

Insert Table 3 about here

Faith and an acceptance of the situation repeated as the tools that most of the patients said they used when dealing with major crises in their lives. Although none of them stated that they considered their current state of being as a major crisis, they all agreed that they were handling their terminal illness in the same manner they had handled previous problems.

Each of the patients were very eager to list and discuss at length previous major crises they had faced. Yet none of them identified their deteriorating health a crisis.

While four of the patients revealed they had made no changes in their lifestyles, most all of them admitted that they had relaxed their standards. They have realized that they are no longer able to accomplish as much as they once were, due to their failing health.

Insert Table 4 about here

Seven of the patients admitted to experiencing a range of emotions from anger to denial to acceptance, with depression and anger being the emotions most often mentioned. Generally, each of the patients admitted bouts of short-term and sporadic depression.

Jill explained: "The most difficult one was anger. It goes against my personality. I get upset and mad at myself because I feel ways I don't want to feel. There was a phase I went through where I questioned why I was the one who was terminally ill. Why couldn't it be my sister? She was the one who was wound up like an eight-day clock. She was the one who was too busy to appreciate life. I hated myself for feeling that way (J. Jordan, personal communication, October

24, 1993)." Only two patients said they did not experience the emotions, but stated that they just accepted the situation.

Insert Table 5 about here

Faith and self-reliance are the major strengths the patients believe have helped them cope with their prognosis. Tom, a hospice patient for five months, explains: "When I feel better, it's easier to cope with this. You can be very noble and inspirational when you feel good. Feeling good is nothing more than feeling less bad (T. Riebert, personal communication, November 2, 1993)."

Their acceptance and/or understanding of their impending death has made their situation easier to handle. Having access to the interdisciplinary hospice team also makes things easier for the hospice patients, too.

Volunteers agreed that their faith and acceptance or attitude towards the situation made it easier to cope. Mary said she and her husband are volunteers who know the outcome: "I think it is our attitude towards the situation. We just accept the fact that they (the patient) are going to go (M. Hilberg, personal communication, November 6, 1993)."

None of the volunteers have had patients who wanted to tell them something. Heather did have a spouse who told her

she was concerned about being left behind once her husband died. Each of the volunteers said that the patient determines if they want to talk with the volunteer, would rather sleep, or just have someone there, without conversation.

Insert Table 6 about here

The difficulties for patients in coping with a terminal illness lie in accepting the physical limitations. While three of the patients listed that as their top difficulty, three others admitted that they did not know what made things more difficult. Relationships, especially in terms of leaving loved ones behind made the circumstances of two patients more difficult to cope with. None of the volunteers interviewed admitted to any difficulties with coping with the deaths of patients.

Mr. Bafford, a 71-year-old farmer, has trouble accepting his limitations. "Some of the things I like to do, I no longer can. I wanted to go to the field this fall and drive. But I can't (F. Bafford, personal communication, October 30, 1993)." Bill echoed his sentiments: "The fact that I cannot do what I used to do -- even simple things like get out of bed, walk, feed myself (B. Balsley, personal

communication, October 30, 1993)."

Tom added a different perspective: "Things that are monotonous. Not having any good distractions. Good distractions can be very precious because they take your mind off your troubles. We're out here in the middle of the prairie where there are not many distractions. Anyone's visit becomes an event (T. Riebert, personal communication, November 2, 1993)."

There were no outstanding communication attempts made by the patient to the volunteer, nor did the volunteers have any concept of what made their hospice work more difficult.

External support systems.

Six of the 10 patients stated they relied on their caregivers and/or family members for emotional support. Two patients said the hospice staff provided the emotional support they needed. Two other patients received emotional support from a friend and their grown children, none of which were considered caregivers.

Insert Table 7 about here

Most of the patients felt free to discuss their concerns and even grief, except Emma. She admitted to

rarely talking about any concerns with anyone. When patients did discuss their impending deaths, they often talked with either their spouse, a caregiver other than their spouse, or the hospice staff.

When they wanted to confide something, most of the patients talked with a caregiver other than their spouse. These were the people they felt they could tell anything and would not be criticized. Only one patient said the question did not apply to her situation.

While patients felt free to talk about their situation, half of the patients admitted that they did not openly grieve over their deteriorating health and impending death. Three of the patients said they sometimes grieved, while two said they seldom did. "I talk about my illness when people want to talk about it. I have found that people who used to be real buddy-buddy now shy away from me. I think it's because they are afraid to talk to me about my illness; afraid they will upset me (F. Bafford, personal communication, October 30, 1993)."

Volunteers also said they received emotional support for their families. Two volunteers received emotional support from the families of their patients.

While most of their family and friends accept their work with hospice, none of the volunteers confide in anyone, nor find it necessary to, in regards to their hospice work.

Monica said her friends don't understand the hospice concept and find it depressing. Julie said her friends were concerned that she was too emotional to be a hospice volunteer.

Changes in Personal Goals

Insert Table 8 about here

Four of the 10 patients said they have not made any changes in their personal goals. Three of the patients have relaxed their standards and/or priorities. Emma said she doesn't fret over her housework to the degree she used to, prior to the advancing of her illness. Two of the patients have realized that they are now the ones being helped, instead of being the helper. This reversal of roles has made both Jill and Phyllis uncomfortable.

Five of the volunteers have not made any changes in their lives since becoming involved with hospice. Heather says her hospice experience has made her realize that if she wants to do something, she should do it and not put it off. Gladys has realized that people and relationships are very

important. Jen realizes she wants to enjoy life and relationships.

Telling people they loved them was the number one message hospice patients wanted to tell others. For the most part, they have been able to tell those whom they love that they love them. Emma and Geneva patients said they didn't know what to tell their loved ones. Tom wanted to make sure his loved ones knew he was thankful for them. Phyllis her family to have faith, and Fae encouraged his sons to have a prostate cancer test.

Fred wanted to settle some things with family members before he died. He contacted a grandson, whom he had disowned several years ago when he learned his grandson had AIDS. Fred asked his grandson to come visit him because he needed to talk with him. His grandson flew from Florida to Illinois to talk with his grandfather. The visit was held on a Sunday afternoon, where Fred asked his grandson to forgive him so that he could die in peace. The grandson did (F. Waltz, personal communication, November 2, 1993). Fred died four weeks later.

Nine of the 10 patients had no suggestions for improvement for the hospice staff. Bill wanted to remind hospice personnel and volunteers to maintain a positive attitude at all times.

Only Bill had anything else to add to the survey. He

wanted it known that he had a good support staff, made up of his wife, family, friends and the hospice team.

Most of the volunteers offered words of support for surviving spouses. Those words included: relying on faith; telling the survivors that they should have no regrets because they did all they could for their loved one; be loving and good to one another at all times; treat everyone special; take one day at a time, and don't forget the good times.

As for advice to improving hospice services, few had any suggestions. Heather did remind the staff that they should try to see things from the patient's and family's perspectives and not judge. Julie cautioned hospice against imposing religious views upon patients. Leon advised the staff to listen to the patients and their families.

Five of the volunteers had additional comments. Julie said she was receiving as many benefits from being involved with hospice as the patients. Dorothy said she knew when she started with hospice that she was where she belonged. Elva encouraged more people to get involved, regardless of age. Gigi and Mary echoed Elva's sentiments.

Discussion

While the patients I interviewed were open to talking about their circumstances, they were often hesitant to talk

about their impending death in front of others. While I have no valid explanation for the hesitation, I believe that it was to spare them any further grief or hurt. Once the person left the room, the patient would again open up and discuss their concerns.

Jill admitted that while she was very close to her mother, who served as her caregiver, she did not always confide in her because she did not want to overburden her (J. Jordan, personal communication, October 26, 1993).

This was a concern of nearly all of the patients, in regards to their caregivers. They were concerned that they were already asking too much of their caregiver by just having them take care of their physical needs.

None of the patients had any suggestions for improvement to the hospice staff. Each of them were content with the level of communication and personal care they received from hospice. This corresponds with Kreps (1988b) who identified a health patient-physician relationship as one with relational health communication competence. Hospice patients expressed comfort in talking with hospice staff about their illness and its implications.

Talking with patients about coping strategies has helped to alleviate some of the fears the patients initially had. In previous studies, it was discovered that patients initially have to work up to sharing their concerns

(Selfridge, 1990). Most of the patients for this study seem to have gotten beyond fears and concerns. They have accepted their situation and are eager to discuss it.

While some studies have demonstrated the value of humor, music, reminiscence or even art therapy as tools for coping, none of these were mentioned by patients completing this survey. Yet nearly all of the patients relayed humorous situations during the interviews.

When discussing the progress of their disease, it was interesting in how each patient categorized their disease as either something that happened suddenly or was slow to progress. The women said the disease was sudden, while the majority of the men said it was slow. Even though the amount of time between when the disease was first diagnosed and when they were interviewed was between two to three years for each patient, the women labeled that timeframe as sudden; while the men said it was slow.

One of the questions asked patients and volunteers was how they had handled previous crises in their lives. There was no question which sought a description of those crises. Yet every patient detailed the major crises in their lives. It was as though they had this burning need to discuss them.

The volunteers, while they listed the crises they had faced, did not go into detail like the patients did. This situation, the patients being very attentive to details and

the volunteers offering little details, repeated itiself throughout the study.

While most of the patients appeared eager to discuss their illness, they admitted to a couple of stumbling blocks in coping with their terminal illness. One of those blocks was in talking with others about their death. The patients admitted to accepting their death, yet they did not talk to others often about it. The reasons for that could be that they wanted to spare others from discomfort, that the patients no longer wanted to think about it, or that others felt uncomfortable admitting that their loved one was dying.

While Jill said she was willing to talk about it, she admitted that she didn't think her friends wanted her to be frank about her death (J. Jordan, personal communication, October 26, 1993). On the other hand, volunteers admitted that they seldom talked about their hospice experiences and saw no real need to do so.

A common thread throughout the study was the existence of faith and self-reliance, as well as acceptance, for both patients and volunteers. For patients, faith was the top contender for nearly each question. For volunteers, faith ranked as one of the top three answers to each of the relevant questions.

Elva, a volunteer for eight years, said faith was a staple in her life, yet she added that she never discussed

faith with a patient unless they wanted to (E. Larson, personal communication, November 6, 1993). She exhibited a pattern that was prevalent among volunteers, where volunteers seemed to react to patient's needs, rather than make any judgements prior to learning of the patient's needs, wants or desires.

Most of the patients do not openly grieve over their approaching death. Fae said it was because he "didn't like to think that way (F. Bafford, October 30, 1993)." At times, I would question if he was experiencing denial or if he was just protecting his feelings. Jill said that on days when she did grieve, she stayed in bed with "the covers pulled up. It helps just to stay out of the way, so you don't get the others down (J. Jordan, personal communication, October 26, 1993)."

A common ground for each of the patients were the love messages they wanted to impart to their families. Many times these messages seemed marked with regret for not getting the message out sooner.

There were major differences between the answers provided by the patients and the ones provided by the volunteers. Where patients seemed eager to divulge information, loaded with details, volunteers did not. Volunteers did not have the rich depth to their answers that the patients did. The reason for that could be that

volunteers are viewing death from a different perspective. First person death is the death from the patient's point of view. Death in the second person requires identification with the dying person and is seen in relation to death of loved ones (McEvoy, 1990).

Perhaps the reason for volunteers to offer so little detail is that they are at least one step removed from death. They have not confronted the issue of their own death to the degree that the dying patient has.

Volunteers were hesitant to initiate conversations with their patients, preferring to let the patient take the lead. While to an outsider that may seem wrong, to the volunteer it makes perfect sense. During the last stages of their lives, patients sleep a lot. Patients reserve their strength for talking only when they want to. The peripheral world does not exist for the dying patient and the volunteer is aware of this fact.

The most surprising element in the answers from the volunteers was their unanimous response that the deaths of their patients had little or no impact upon their lives.

Also, while faith and self-reliance were major strengths to the patients, the volunteers downplayed the role. Even though faith was prominent in several of the lives of the volunteers, it was not as widespread.

Communication was also downplayed. Volunteers admitted

that they did not regularly confide in anyone about their hospice experiences. Yet patients did. Again, the reason for the difference could lie in the removal of the volunteer from their own death.

Future Studies

Future studies between the patient and his/her volunteer might provide better insight into coping mechanisms of the terminally ill. Patients mentioned having to reduce their standards of acceptance. Volunteers mentioned that they have learned to not delay doing things they have wanted to do, or say things that needed to be said. Studying these two concepts would provide insight not only into how a person copes with his or her death, but also the priorities in life, and what makes them priorities.

How communication is prioritized in the life of a dying person is another area of study. This study would determine the value the hospice patient places on communication and study any adjustments in that value the patient might have.

Further investigations of this type of study need to be performed, in order to verify not only this study's findings, but also to verify that coping strategies are necessary to the positive experiences of those associated with hospice.

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Table 1

Strengths in coping with hospice situation

Item	Patient		Volunteer	
	Female	Male	Female	Male
Faith/self reliance	4	4	3	0
Attitude	1	0	1	0
Don't know	1	0	2	1
Listening	0	0	2	0
Non-judgmental	0	0	1	0
Patience	0	0	1	0

Table 2

Coping strategies with other major crises

Item	Patient		Volunteer	
	Female	Male	Female	Male
Anger	1	0	0	0
Acceptance	2	2	1	0
No crises	0	1	2	0
Faith/self reliance	3	1	2	1
Don't know	0	0	4	0
Being involved	0	0	1	0

Table 3

Role of faith

Item	Patient		Volunteer	
	Female	Male	Female	Male
Major	5	2	6	1
Minor	0	2	2	0
None	1	0	2	0

Table 4

Emotions experienced

Item	Patient		Volunteer	
	Female	Male	Female	Male
Depression	3	3		
Anger	3	2		
Acceptance	1	1	10	1
Denial	1	1		

Table 5

Coping efforts to make it easier

Item	Patient		Volunteer	
	Female	Male	Female	Male
Acceptance/attitude	2	2	3	0
Support	2	1	1	0
Understanding	2	0	0	0
Faith	1	0	2	1
Making a difference	0	0	1	0
Don't know	0	0	3	0

Table 6

Difficulties in coping

Item	Patient		Volunteer	
	Female	Male	Female	Male
Relationships	2	0	None of volunteers had insights to this	
Physical limitations	0	3		
Don't know	3	0		
Monotony/waiting	1	1		

Table 7

Emotional support provider

Item	Patient		Volunteer	
	Female	Male	Female	Male
Caregiver/family	3	3	7	0
Hospice staff	2	0	0	0
Friend	0	1	0	0
Church/God	1	0	0	1
Patient's family			2	0
Don't know	0	0	1	0

Table 8

Changes in personal goals

Item	Patient		Volunteer	
	Female	Male	Female	Male
Role reversal	2	0	0	0
Priorities/standards	2	1	2	0
Relationships	1	0	1	0
Routines, daily, weekly	0	0	4	0
None	1	3	3	1

Appendix A

Survey of the coping strategies of the hospice patient

Thank you for volunteering to visit with me about your experiences as a hospice patient. Your responses will be kept confidential. You may stop at any time, just let me know. The visit should not take longer than an hour, but if you would like more time, that is OK. Do you have any questions or concerns before we start?

1. How long have you been in the hospice program?
2. How old are you?
3. Tell me about your illness. Was it sudden, or have you had the condition for some time? What does this illness and its implications mean to you?
4. How have you dealt with other major crises in your life? Have you been able to use the same approaches in dealing with this situation?
5. What changes have you made, in regards to priorities in your life, since becoming a hospice patient?
6. Which of your strengths are most helpful to you during this time?
7. What role has your spiritual faith played in this?
8. Who are you relying on most during this time to help you with emotional support?

Spouse	Relatives	Hospice staff	Neighbors
Friends	Children	Pastor/priest/rabbi	Others

9. To what extent do you openly discuss your illness?

Not at all	Rarely	Sometimes	Frequently	Always
1	2	3	4	5

10. With whom can you openly discuss your illness?

Spouse	Children	Hospice staff	Good friend
Neighbor	Pastor/priest/rabbi		Others

11. Do you have someone you can confide in, who accepts your grief and concerns, without criticism? If so, is this helpful? Who is that person? If not, would this be helpful? Who would you like that person to be?
12. To what extent do you openly grieve? Do you feel you can? If not, why not?
13. Often those in the hospice program experience a range of emotions, from anger to denial, bargaining, depression and finally, acceptance. Have you experienced these emotions? Would you describe those experiences? Have you experienced all of them, some or have you repeated some of the emotions?
14. Have you begun to experience a calming, healing acceptance of your situation? How and when did that happen? If it has not yet happened, do you anticipate it? What would cause it to come about?
15. What sorts of things make it easier for you to accept your illness?
16. What sorts of things make it more difficult for you?
17. If you could tell your loved ones anything, what would that be? Have you told them? Why or why not?
18. If you could tell the hospice staff anything that would help them be more sensitive to hospice patients and their loved ones, what would that be?
19. Is there anything else you would like to share?

Thank you for helping with this study.

Appendix B

Survey of the coping strategies of hospice volunteers

Thank you for volunteering to visit with me about your experiences as a hospice volunteer. Your responses will be kept confidential. You may stop at any time, just let me know. The visit should not take longer than an hour, but if you would like more time, that is OK. Do you have any questions or concerns before we start?

1. How long have you been a hospice volunteer?
2. How many patients have been assigned to you?
3. How would you describe your relationship to the patients?
4. How long had you been a volunteer before you experienced the death of your first patient? Were you with the patient at the time of death? Describe your experience.
5. Has that death affected your relationships with other patients? What type of impact did the death have upon you?
6. How have you dealt with major crises in your life? Have you been able to use the same approaches in dealing with the loss of a patient?
7. What changes have you made in your life since becoming a hospice volunteer?

Daily routines
Priorities

Plans for the future

8. Which of your strengths were most helpful to you in dealing with your loss?
9. How has your spiritual faith helped you during the death of a patient?
10. Who do you rely on most to keep you going during the time when death is imminent for your patient?

Spouse

Relatives

Other hospice volunteers

God

Friends

Pastor/priest/rabbi

Children

Neighbors

Others

11. To what extent do they encourage you to openly grieve?
- | | | | | |
|------------|--------|-----------|------------|--------|
| Not at all | Rarely | Sometimes | Frequently | Always |
| 1 | 2 | 3 | 4 | 5 |
12. To what extent **do** you openly grieve?
- | | | | | |
|------------|--------|-----------|------------|--------|
| Not at all | Rarely | Sometimes | Frequently | Always |
| 1 | 2 | 3 | 4 | 5 |
13. Do you have someone you can confide in who will accept your grief and concerns without criticism? If so, is this helpful? If not, would it be helpful?
14. Do your friends and loved ones accept your work with hospice? How do they view your hospice experiences (positive, morbid)?
15. What sorts of things make it easier for you to deal with the deaths of patients?
16. Have any of your patients wanted to tell you some things that they had not mentioned to anyone else? What were the nature of the conversations?
17. How much of the time you spent with the patient was in communicating? Was all communication verbal, or were there nonverbal messages and body language? What were they? Could you understand the patient?
18. Do any communication attempts from the patient stand out in your memory? Describe them.
19. What sorts of things make the deaths harder for you?
20. If you could tell others who have lost loved ones anything from your perspective that would be helpful to them, what would it be?
21. If you could tell the hospice staff anything that would help them be more sensitive to the patient and the caregivers, what would that be?
22. Is there anything else you would like to share?

Thank you for helping with this study.