

2001

# Maine hospice volunteers: a study of motivations, death awareness and religious beliefs

Anne F. Donovan

Follow this and additional works at: <http://digitalcommons.library.umaine.edu/etd>

 Part of the [Social and Behavioral Sciences Commons](#)

---

## Recommended Citation

Donovan, Anne F., "Maine hospice volunteers: a study of motivations, death awareness and religious beliefs" (2001). *Electronic Theses and Dissertations*. 502.

<http://digitalcommons.library.umaine.edu/etd/502>

This Open-Access Thesis is brought to you for free and open access by DigitalCommons@UMaine. It has been accepted for inclusion in Electronic Theses and Dissertations by an authorized administrator of DigitalCommons@UMaine.

**MAINE HOSPICE VOLUNTEERS: A STUDY  
OF MOTIVATIONS, DEATH AWARENESS  
AND RELIGIOUS BELIEFS**

By

Anne F. Donovan

B.S. The University of Maine, 1999

A THESIS

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Master of Science

(in Human Development)

The Graduate School

The University of Maine

May, 2001

Advisory Committee:

Marc D. Baranowski, Associate Professor of Human Development, Advisor

Gary L. Schilmoeller, Associate Professor of Child Development & Family  
Relations

Elizabeth H. Bicknell, Associate Professor of Nursing

**MAINE HOSPICE VOLUNTEERS: A STUDY  
OF MOTIVATIONS, DEATH AWARENESS  
AND RELIGIOUS BELIEFS**

By Anne F. Donovan

Thesis Advisor: Dr. Marc. D. Baranowski

**An** Abstract of the Thesis Presented  
in Partial Fulfillment of the Requirements for the  
Degree of Master of Science  
(in Human Development)  
May, 2001

Volunteers are **an** essential part of the hospice movement, which is designed to provide services to the terminally ill, their families, and friends, in a manner that allows death to be as dignified and peaceful as possible. Motivations for volunteering, attitudes about death and dying, and demographic characteristics were assessed in this survey study of Maine hospice volunteers (573 females, 128 males). The extent to which religious and spiritual beliefs were associated with volunteers' ability to cope with the many aspects of death and dying that they confront were also examined. Based on responses to a standardized instrument, the Collett-Lester Fear of Death and Dying Scale, respondents' reported relatively low levels of death anxiety and high levels of death awareness for themselves and others in their lives. The most common reasons for becoming a hospice volunteer were: desiring to help persons in need, wanting to ease the pain of those in hospice programs, having unique expertise to contribute, wanting to fulfill a civic responsibility, and wanting to fulfill a religious obligation. Sixty-five percent of the sample reported that spiritual beliefs had a major influence on their ability to cope with death and dying. The results provide information that can be of assistance in the recruitment, training, and education of hospice volunteers in Maine.

## ACKNOWLEDGEMENTS

Without the interest and participation of each hospice program in the state of Maine, their volunteers, directors, and volunteer coordinators this research would not have been possible. I sincerely want to thank each hospice program. I thoroughly enjoyed traveling to each program, visiting their facility and getting to know them as a unique hospice. In addition, I would like to thank the Maine Hospice Council for their cooperation in making the information available to me so that I could research the hospice programs in Maine in a thorough manner.

Of course, completing a master's thesis is not done alone. My professor, advisor, committee chair, and mentor Dr. Marc D. Baranowski, who supported, encouraged, pushed, and advised me when needed is to be thanked. I truly appreciate all the hours and dedicated help he offered me throughout my college career. In addition, I want to thank the rest of my thesis committee members: Dr. Gary L. Schilmoeller who taught me not only to write a thorough research paper, but also to critically read others, and Elizabeth H. Bicknell whose expertise in nursing and the needs of the elderly population added to the quality of this thesis. A sincere thank you goes to Janice Bacon for her patience and technical support. I am extremely grateful to Chantelle Haltizer for her friendship and encouragement throughout graduate school and the thesis experience.

A loving thank you to my sons, Joseph and Timothy, who not only supported me throughout my college career but also kept me balanced as to what is important in life. Sincere thanks to my mother, Rosemary, who saw the best and worst in me during the thesis process and continued to review my writing and offer suggestions when needed. And Dale, thank you for simply understanding and watching as I work toward my dream.

Lastly, I dedicate this thesis to my father, Timothy Justin Donovan, who died when I first began my college journey. My father not only introduced me to what hospice care provides individuals and their families, but also placed it in my heart.

## TABLE OF CONTENTS

ACKNOWLEDGEMENTS.....	ii
LIST OF TABLES.....	vi
Chapter	
I. Literature Review.....	1
Motivations of the Hospice Volunteer.....	3
Coping and Stress of the Hospice Volunteer.....	8
Death Anxiety and Death Awareness of the Hospice Volunteer.....	14
Purpose of Study.....	21
Research Questions.....	22
II. Methods.....	23
Sample and Procedure.....	23
Instrument.....	24
Data Analysis.....	27
III. Results.....	28
Volunteer Activity.....	28
Question 1.....	28
Question 2.....	31
Question 3.....	31
Hypothesis 1.....	33
Question 4.....	35

Question 5 .....	35
Responses to the Open-Ended Item .....	35
IV. Discussion.....	40
Study Limitations.....	45
Implications for Future Research.....	45
REFERENCES.....	47
APPENDIX A Informed Consent Sheet.....	51
APPENDIX B Maine Hospice Volunteer Survey.....	52
APPENDIX C Participating Maine Hospice Programs.....	56
APPENDIX D Survey Comments.....	58
"Giving Back" .....	58
Comments that Characterize the Religious and Spiritual Benefits of Hospice Volunteering.....	59
Comments on the Hospice Philosophy and Program.....	60
Rewards of Hospice Volunteering.....	61
Comments on Death and Dying.....	66
BIOGRAPHY OF THE AUTHOR.....	71

## LIST OF TABLES

<b>Table 1</b> - Demographic Characteristics of Respondents..	25
<b>Table 2</b> - Volunteer Activity of Respondents..	29
<b>Table 3</b> - Volunteer Motivation Mean Scores..	30
<b>Table 4</b> - Mean Death Anxiety Subscale Scores by Sex..	32
<b>Table 5</b> - Pearson Correlations Between Death Anxiety Subscales and Predictor Variables..	34
<b>Table 6</b> - Are Religious and Spiritual Beliefs Associated with Individuals' Obligation to Volunteer for Hospice?..	36
<b>Table 7</b> - Are Religious and Spiritual Beliefs Associated with Individuals' Ability to Cope with Issues of Death and Dying..	36

## Chapter I

### Literature Review

*Getting well is not the only goal. Even more important is to live without fear, to be at peace with life, and ultimately death.*

- Bernie S. Siegel, M.D. (1986). *Love, Medicine and Miracles*.

Hospice care is based on a set of coordinated services that are intended to relieve, or at least ease, the symptoms and side effects of a terminal illness. The care hospice provides usually occurs in the homes of the dying patient where family and friends can keep the individual comfortable in a familiar surrounding (Beresford, 1993). The primary theme of hospice is illustrated by Beresford (1993), “hospice is not a place where patients go to die: it is a service that comes to wherever the patient is living” (p. 9). Hospice care attends to the whole person: mind, body and soul. Hospice involves an interdisciplinary team approach to care that includes physicians, nurses, social workers, counselors, clergy, and volunteer services on a twenty-four hour, seven day a week need basis. Hospice tries to support the traditional strengths and coping skills of dying individuals and their families. In that care hospice pays attention to the needs and concerns of the family, and offers extra help when needed. Hospice care does not end when the patient dies; a bereavement team is available to the families and friends of those that died for a year or more after the death (National Hospice and Palliative Care Organization, 1999).

The philosophy of hospice is that it affirms life. Hospice provides support and care for those in the last stages of an incurable disease so that they can live as fully and comfortably as possible. Hospice views dying as a normal process and neither hastens

nor postpones death. Hospice also believes that appropriate hospice care for the patient and family members enables them to maintain mental and spiritual preparation for death. The following criteria need to be agreed upon in order for an individual and their family to receive hospice care and reflects what most hospice programs use as a criteria

(Hospice of St. Joseph, 1997):

- 1) The patient/family understands the Hospice concept of care as being palliative and not curative in its goals.
- 2) The patient/family understands the Hospice concept of care requiring the active participation of the family, if any, as caregiving members of the Hospice team consistent with the capabilities of the family.
- 3) The terminal prognosis (six months or less) of the patient is confirmed by the physician.
- 4) Race, color, creed, religion, sex, sexual orientation, age, or national origin shall not be used as criteria for admission.
- 5) The patient/family understands that Hospice retains responsibility for determining the appropriate location for treatment.
- 6) Referrals may be made by the patient, family member, physician, clergy, friend or other care provider. No referral should be made without patient knowledge and consent. The patient's personal physician, if unaware of the referral, should be contacted immediately to ascertain receptivity to the referral to hospice.
- 7) The final decision as to whether a patient meets admission criteria to be admitted as a Hospice patient shall be made by the Hospice.

In 1998 hospice care touched the lives of nearly 540,000 people in the United States (National Association for Home Care, 1999). The hospice movement in the United States began twenty-six years ago, but hospice care has a long history dating back to the Middle Ages when religious institutions cared for the sick and elderly in their churches and temples (Siebold, 1992). In 1974 the first hospice in the United States officially opened, the Hospice of Connecticut in New Haven. Within three years the National Hospice Organization was formed which provides hospice standards and guidelines for the growing number of hospices being organized and opened in the United States (Mor, 1987).

**An** integral part of the hospice movement is the commitment and enthusiasm of the hospice volunteer. Laliberte and Mor (1988) state that the involvement of the hospice volunteer has allowed the existing health-care systems to begin to recognize, accept and incorporate the hospice philosophy into its current practices. Cox (1979) states that it is because of the commitment of the hospice volunteer that other hospice programs have been established across the United States. Julie K. Ballo (1991), director of volunteer services at the Kaiser Permanente Los Angeles Medical Center states that, “volunteers do not provide medical care; rather, they offer caring, assistance, and social and emotional support... a type of care that is less centered around high-tech equipment and more around high-quality care given by people” (p. 24).

#### Motivations of the Hospice Volunteer

Clearly, hospice volunteers are an important component of hospice programs. Due to the growth of the hospice movement in the last twenty-six years, many researchers have been interested in what motivates an individual to volunteer for a hospice program (Black & Kovacs, 1999; Murrant & Strathdee, 1995; Patchner & Finn, 1987; Scott & Caldwell, 1996). Other researchers examined whether there were specific characteristics that were unique to the hospice volunteer (Briggs, 1987; Finn-Paradis & Usui, 1987; Mitchell & Shuff, 1995; Sadler & Marty, 1998; Wilkinson & Wilkinson, 1986-87).

Hall and Marshall (1996) sum up three core conditions that they believe enable a hospice volunteer to become successful. The first core condition is the hospice volunteer’s congruence, meaning the hospice patient senses they are dealing with a

genuine and “real” person. The second core condition is that hospice volunteers communicate unconditionally. This means the volunteer will care for the hospice patient without judging their thoughts, feelings or behaviors as good or bad. The third core condition, and usually the most difficult to achieve, is empathic understanding about what the individual is experiencing.

Patchner and Finn (1987) surveyed 102 hospice volunteers to explore their satisfaction, performance, motivations for volunteering, and attitudes toward death and dying. The results indicated that overall the volunteers were motivated by their religious beliefs and personal experience. Eighty-eight percent of the volunteers stated that they had experienced a death of a significant person in their lives, and about half of these death experiences were the death of their parent. In addition, the volunteers saw their role in hospice as important. Eighty-six percent of the volunteers stated that they felt totally prepared for their duties as a hospice volunteer, especially the duties that brought them in direct contact with the patients and families seeking hospice care. Interestingly, most had a strong belief in life after death, and the importance of loss and grief work was primary to hospice work.

Recently, Black and Kovacs (1999) explored the effects of age of the hospice volunteer, what motivated them to become hospice volunteers and their level of satisfaction in a survey of 222 hospice volunteers. The researchers discovered that the age of the volunteer directly influenced the type of volunteer role they fulfilled. The older the volunteer, the more apt they were to conduct clerical and fund-raising duties. Younger volunteers were more likely to directly work with patients and families seeking hospice care. This research offers valuable information to hospice directors and

volunteer coordinators in areas of recruitment, retention, and type of duties needed to be fulfilled in the volunteer capacity. Most importantly, the researchers state that the age of the volunteer is not as important as their desire to help others.

Scott and Caldwell (1996) sent questionnaires to fifty hospice programs in Texas to administer to their hospice volunteers asking about their motivations and reasons for being and staying involved in a hospice program. From the 156 returned questionnaires, most volunteers indicated that the availability and use of a volunteer support group was an integral piece in their ability to cope and stay motivated in their volunteer work. In addition, many of the hospice volunteers stressed the need for continued training programs that focused on issues of hospice and hospice care. The volunteers stressed that being involved in support groups and training programs specifically designed for hospice was important because it also kept them connected to others who work and volunteer for hospice.

Murrant and Strathdee (1995) explored the motivations of twenty-one **AIDS** hospice volunteers by administering questionnaires three months and one year following their hospice training and orientation programs. Overall, the volunteers stressed an overwhelming desire to be involved in a hospice program in addition to seeking personal growth. The researchers state that the volunteers entered the program without predetermined expectations, and therefore it is difficult to recognize their conscious motivations. Lastly, the volunteers continued their volunteer work because they felt supported, valued and respected by the staff members at the **AIDS** hospice center.

Finn-Paradis and Usui (1987) studied characteristics of **113** Kentucky hospice volunteers. They believe that there are specific traits that most hospice volunteers have

and they sought to explore what those traits were by using several types of measures: the Volunteer-Personal Information Form, the Self-Evaluation Questionnaire, the Personal Reaction Inventory, and the Volunteer Job Performance Rating. The researchers found that the most successful hospice volunteers were middle-aged or older, were economically stable, were employed and had previous experience in other types of volunteer work. The findings demonstrated that the hospice volunteers in this study gained high levels of empathy toward issues of the dying individual. Two instruments were used to measure issues of death: the Bugen Coping with Death Scale, and the Winget Questionnaire for Understanding the Dying Person and His Family. The last two measures focused on death anxiety and awareness, and the researchers conclude that in this study the volunteers displayed high levels of understanding the needs of the dying. Finn-Paradis and Usui claim that this type of research is vitally important for the basic reason that hospice volunteers are the backbone of the hospice movement and understanding what motivates a volunteer to continue their work is valuable overall to the hospice program.

Wilkinson and Wilkinson (1986-87) conducted a study of forty-one hospice volunteers who had completed their volunteer training program. Five measures were used in this study to examine issues of external versus internal control, anxiety, **and** empathy along with issues of coping and death. The results showed that the volunteers were relatively low in anxiety, generally internally controlled, had a strong ability to be empathic, and scored high in their abilities to cope and deal with death. By exploring the characteristics of hospice volunteers, like the Wilkinsons' research has done, other hospice directors and volunteer coordinators can implement this information for their

own hospice programs. Research like this enables hospice programs to continually offer volunteer trainees in the training program up-to-date and supportive information pertaining to their role in the hospice program.

Mitchell and Shuff (1995) conducted a study that measured the personality traits of hospice volunteers. They chose to use the Myers-Briggs Type Indicator to assess ninety-nine hospice volunteers in a large southern metropolitan area. The results revealed that most of the ninety-nine hospice volunteers were more extroverted than introverted, more intuitive than sensing, and more feeling than thinking in their personality assessment. It was suggested by the researchers that the elements of sensing and intuition are integral aspects of volunteering, especially for a hospice program.

A measurement was developed by Briggs (1987) that differentiated the qualities of hospice volunteers who remained active in their volunteer work compared to hospice volunteers who were now inactive in their service. Briggs sampled 166 volunteers from two hospice programs and concluded that active and inactive volunteers differed from each other in two important areas: active volunteers were more apt to work well as team members and displayed more flexibility in their ability to deal with issues and situations that often arise in hospice work.

Sadler and Marty (1998) examined seventeen people who participated and completed their hospice training and became active as volunteers within a one-year period. The researchers interviewed each of the participants for one hour to determine their reasons for becoming a hospice volunteer. The researchers discovered that there were specific “turning points” that helped define the participant’s success as a hospice volunteer. According to the researchers, a “turning point” consists of certain moments

when the hospice volunteers knew they should either become or remain a volunteer. The most prevalent pre-hospice turning point was that they became hospice volunteers to learn more about death and dying. The interpersonal turning point was when the hospice volunteers felt their success as a hospice volunteer was directly connected to the quality of their interactions to the hospice staff both during and following the training program. The final turning point was the group turning point, which meant the participants felt positively about their small group interactions, structural support, recognition, status, and membership they received while being a hospice volunteer. Clearly, hospice volunteers find contact with other hospice staff as a major source of identification in addition to their actual volunteer hospice work.

In summary, the body of research that has investigated the motivations and characteristics of hospice volunteers indicates that the hospice volunteer has a desire for personal growth and to help others. Hospice volunteers tend to be good empathic listeners and understand the needs of the dying. Hospice volunteers were generally motivated by their own religious beliefs and experiences and believe that there is life after death. Many hospice volunteers stressed that being involved in support groups and training programs designed especially for hospice volunteers was not only important as a form of connection to other volunteers, but also in their ability to cope and stay motivated in their volunteer work.

### Coping and Stress of the Hospice Volunteer

Volunteer motivations and characteristics also impact ability to cope with the stress involved in most hospice work. Munley (1983) explains how this stress translates

into the volunteer role, “because people are terminal they require a much more intense output of effort. Death itself isn’t stressful. It’s the management of the energy that is stressful”. She concludes, “if somebody is dying, you can’t say I’ll be back tomorrow” (p. 190). In-depth research has been done pertaining to the issue of volunteer stress and burnout when it comes to hospice care. Out of this research valuable insight has occurred that allows for better understanding and prevention of possible causes of stress and burnout.

According to Glass and Hastings (1992), it is often new volunteers and those with little experience who are prime candidates for stress and burnout. They explored role expectations and motivations of the hospice volunteer and how that factors into stress and burnout. The researchers found that during the training volunteers need to clearly understand how their role as volunteers meshed with each member of the patient care team. They add that four key elements need to be addressed when looking at the overall issue of role expectations of the hospice volunteers. The first key element is that lines of authority need to be clarified, that is, from whom do volunteers take directions? Second, goal setting and team building among the entire patient care team need to be accomplished. Third, opportunities for social support must be provided to hospice volunteers. And fourth, hospice volunteers must be allowed to redesign their tasks and schedules when needed. An attempt to work at individual and group levels of stress is often a primary focus for many hospice programs. According to Glass and Hastings (1992), hospice programs need to be fully aware and supportive of their volunteers because working with the terminally ill and their families can be emotionally exhausting. In order to maintain the emotional health of a volunteer the hospice program needs to

provide a safe haven for the hospice volunteer to go to so they can receive the support and reprieve when needed.

Lafer (1991) focused upon issues important to the volunteer coordinator, especially what can be done to remove and alleviate sources of burnout that most often occur. Diminishing the attrition levels of hospice volunteers lies in four basic areas according to Lafer. The selection process of the volunteers is the first area of importance. Generally speaking, hospice programs do not accept anyone for volunteer training who has experienced a significant death in the last twelve months. Though bereavement and grief issues do not “go away” within twelve months of a loss, hospice believes it important for any prospective volunteer to have time needed to work through some of the immediate issues pertaining to the death of a loved one. Most hospice programs encourage those who have lost a loved one to wait approximately twelve months prior to committing to a hospice volunteer program (DuBois, 1980; Kavanagh, 1983; Vachon, 1987). Lafer (1991) suggests that an extensive interview, along with a brief personality questionnaire, be administered to any hopeful hospice volunteer candidate.

The second area pertains to the type of training the potential hospice volunteer receives. A myriad of issues needs to be addressed in hospice training and should be routinely evaluated as to whether they need updating. Most hospice training programs involve the following important issues:

- Hospice philosophy
- Hospice interdisciplinary team
- Spiritual dimensions of hospice care
- AIDS and infectious disease prevention
- Psychodynamics of the hospice patient and family
- Personal death awareness
- Physical care/symptom management and pain management
- Hospice resource people

- Stress management
- Stages of dying
- Ethics
- The volunteer role
- The emotional impact of funeral planning
- Empathic communication skills
- Psychological perspectives on death and dying
- The grieving process and bereavement

Beyond these listed, the role of the volunteer is often tailored to fit the needs of the patient and family. Some of the ways a volunteer serves the patient and family are: personal care, patient/family support, entertaining patients (reading books, playing cards, listening to music, etc.), spiritual support, housework, and errands, to name a few (Stephany, 1984). Ultimately, because the basis of the hospice philosophy is individual care, the role of the hospice volunteer will depend on the specific needs and situation of each individual and family. In addition, volunteer roles will change as the program changes, as new people enter the program, and as the volunteers themselves change (Kavanagh, 1983).

Third, what is the transition from training to actual volunteer work? Often volunteers are not called upon for months after they complete their training. Kavanagh (1983) explains that this is because some new volunteers do not feel confident or ready to be assigned a hospice home visit like they thought. How that affects their motivation and commitment to the volunteer work varies. Kavanagh states that it is important for the volunteer coordinators to stay in direct contact with their volunteers, whether active or not, and know them individually. Once the hospice volunteers are active they should be carefully supervised until it is apparent they are ready and confident in their duties.

The fourth issue is the type of supervision and support hospice volunteers receive from the administrators of the hospice program. The commitment and goals of

volunteers need to be closely monitored by the hospice coordinator. The reasons for attrition of the hospice volunteer are varied and complex. A finely tuned hospice volunteer selection process, training program, and monthly volunteer meetings are integral aspects of the overall success of hospice programs and the care they offer families and those terminally ill. Lastly, Kavanagh (1983) believes that the hospice coordinator is the individual who “represents the hospice to the volunteers and the volunteers to the hospice” (p. 220).

Finn-Paradis, Miller, and Runnion (1987) sought to identify sources of volunteer stress. Thirty-eight hospice volunteers participated and were asked four open-ended questions about their concerns of stress and burnout pertaining to hospice volunteer work. They were asked to identify any concerns or problems from the training program, how long they expected to stay a hospice volunteer, and their motivations for either staying or leaving. From these four questions the researchers were able to conclude that volunteer stress fell into four categories:

- 1) Role ambiguity – This refers to being unclear or conflicted in their role with the hospice program. For example, should they attend the interdisciplinary team meetings? Does the staff want my input on how the patient is doing?

- 2) Status ambiguity – This refers to where they see their “role” in hospice land in the overall hierarchy of the hospice program. For example, because of my volunteer status, does the staff really want to know how I think the patient is doing when a nurse is also visiting and reporting on the same patient?

- 3) The stress involved working with patients and their families – This involves a volunteer feeling pressured to take care of too many people and issues at one time. For

example, though my primary concern is the patients, I am aware that their family is requiring a lot of attention. How do I handle that?

**4)** The stress involved due to one's own personal circumstances – This refers to pressures outside the hospice program that affect ability to volunteer. For example, demands by family or paid work that require you to cut down the number of hours you currently volunteer.

The researchers believe that these four areas of stress can be reduced with a well designed volunteer training program. Hospice volunteers stay motivated and active, or become inactive in their volunteer work for a variety of reasons. If the volunteer coordinator and administration better understand the reasons for leaving and staying in the volunteer position, it will benefit the overall hospice program. Lastly, according to Finn-Paradis, Miller, and Runnion, volunteer training should have three purposes. One is to allow volunteers to learn the many different roles they may fulfill as a hospice volunteer. The next is to provide all basic information about the needs of the patients and their families. The third is to realize that not all trainees are ready or able to work with the patients and families looking for hospice care. It is advised that, at the onset of training, potential volunteers be informed of their expected duties and responsibilities so that the selection process can begin immediately.

In summary, hospice volunteers indicate that having volunteer support groups and training programs are important in maintaining their ability to cope and stay motivated in their volunteer work. It is also important for hospice volunteers to receive thorough training and clear communication about what their roles and responsibilities are in the hospice program. Hospice volunteers are an integral part of the hospice interdisciplinary

team. By clearly understanding the possible risks and stresses of that role, hospice programs can proactively maintain healthy, active and committed volunteers. And lastly, hospice volunteers expressed that one of the many reasons they continue to volunteer for hospice is because they felt valued, supported and respected by other hospice staff members.

### Death Anxiety and Death Awareness of the Hospice Volunteer

In addition to studying the motivations and characteristics of hospice volunteers, researchers have also been interested in their levels of death anxiety and awareness. Morgan (1995) states that death awareness is about bringing death back into the consciousness and therefore making it more human. Death anxiety is most often referred to in the literature as an intense fear, or anticipation of, your own death or the death of another individual. Cunningham and Brookbank (1988) write that there are no answers for death anxiety because, "it is impossible for anyone to conceive of him- or herself as not existing" (p. 225). Tomer (1994) defines death anxiety as being caused by the anticipation of the "state in which death occurs to all that is living, including your own death (p. 3). Burnell (1993) counseled dying patients and their families and discovered that individuals experience seven layers that underlie their fear of death, often called death anxiety.

- 1) We fear the experience of dying itself: Under what condition are we going to die? Will there be much suffering? How much pain will there be? How much control will we have over the pain?
- 2) We fear a lingering death in a nursing home.
- 3) We fear the feeling of being ashamed and losing our dignity.
- 4) We fear nothingness... the ceasing to be.
- 5) We fear being alone when we die and being separated from our loved ones.

- 6) We fear that tubes, machines, and devices will take over to maintain our bodily functions and control our body for the remaining time in our life.
- 7) We fear failure.  
(p. 28-30).

In addition, Wentzel (1981) suggests that hospice volunteers are also, “motivated by the priceless opportunity to learn about the dying process; to learn about courage and dignity... to learn about the all-rightness of death” (p. 82). It has been suggested that other possible factors that motivate an individual to volunteer for hospice may be previous personal experience with hospice and other forms of pain and loss experienced in life (Uffman, 1993; Vachon, 1987; Wentzel, 1981). Overall, Uffman (1993) stresses that successful hospice volunteers are, “at peace with death and dying... able to face their own mortality without fear... comfortable with people who are in the final stages of life... aware that they don’t have all (or any) of the answers... and comfortable with not knowing” (p. 88).

Interestingly, research indicates that hospice volunteers generally score low on death anxiety and high on death awareness (Amenta, 1984; Robbins, 1991, 1992). Other research shows that, due to the volunteer training program that most hospice programs mandate, volunteers experience a decrease in their generalized conscious fear of death, but an increase in their conscious fear of others’ death. The researchers explain this as a difference between the perception of control over internal and external fears (Hayslip & Walling, 1985-86). Research conducted by Tamlyn and Caty (1985) and Werner (1990) suggests that volunteers who receive thorough death education during hospice volunteer training are often more aware and able to help the terminally ill and their families through the dying process.

Amenta (1984) wanted to learn more about death anxiety and purpose in life among hospice volunteers. Much of Amenta's research is based on Frankl's (1959) belief that individual meaning and purpose in life is associated with the individual accepting and finding meaning in suffering and death that also occurs in life. With that in mind, Amenta contacted forty-two trained hospice volunteers and administered both the Templer Anxiety Scale and Crumbaugh and Maholick's Purpose of Life Test to measure the volunteer's levels in death anxiety and purpose in life. The results clearly indicate that those volunteers who persisted (eighteen left the program between the fourth and eleventh month after training) scored high in purpose of life and low in death anxiety. Amenta's research supports the thought that those comfortable with hospice work often show characteristics of having faced the reality of their own death and the ability to work well with those who are dying.

Robbins (1991) used the revised Templer/McMordie Death Anxiety Scale along with several other measures to explore 248 hospice volunteers' levels of self-actualization and their death concern. Robbins hypothesized that since hospice volunteers face mortality, they ought to be more self-actualized. As expected, the death anxiety scores were relatively low in the 248 hospice volunteers. Those volunteers who scored low in death anxiety generally scored high in their ability to self-actualize. Robbins concluded that issues of death anxiety and awareness are useful in researching hospice volunteers and their levels of self-actualization in the process of confronting mortality.

Robbins (1992) also conducted research that focused on coping with death and dying among four separate groups of participants. The first three were hospice

volunteers: fifty-two hospice volunteer trainees, ninety-four who had volunteered for hospice for no more than four years, and ninety-six with over four years experience as hospice volunteers. The fourth group was a control group of seventy-eight non-hospice volunteers. Robbins examined whether the four groups differed in their ability to deal and cope with death and dying. The measure used was Bugen's Coping with Death Scale, which predicts behavioral preparedness of death. The results reveal that the ninety-four who had volunteered for hospice for no more than four years, and the ninety-six with over four years experience, scored significantly higher than the fifty-two volunteer trainees and the seventy-eight non-hospice volunteers in their ability to cope with death and dying.

Hayslip and Walling (1985-86) sought to examine the death anxiety and locus of control in fifty-nine research participants, twenty-nine of whom were hospice volunteers and thirty who were identified through a hospice mailing list but were not volunteers. Both the volunteer group and the non-volunteer group underwent the same training program that lasted eight weeks. Participants were assessed using the Collett-Lester Fear of Death Scale, which measure conscious fear of death, and the Templer Death Anxiety Scale, which measures generalized death anxiety. Interestingly, after the pretest and posttest results were examined, it was discovered that both groups decreased in their overall conscious fear of death, but there was an increase in their conscious fear of others' death. There was also an overall decrease in both groups' unconscious death related issues like loss of control, and other covert types of death anxiety. The researchers concluded that the hospice training program seemed to sensitize the participants to issue of the uncontrollability of death and dying.

Tamlyn and Caty (1985) suggest that hospice volunteers who receive training in death education are often more aware and empathic about the processes of dying and the needs of the family. Death education according to Tamlyn and Caty comprises the many issues that are associated to the dying process like communication about loss and bereavement, and ethical issues related to terminal illness. They compared the scores of forty hospice volunteers before and after death education training using the Questionnaire for Understanding the Dying Person and His Family. The results indicated that death education produced a statistically significant increase in overall positive death attitudes in hospice volunteers.

Werner (1990) conducted a similar study with a control group that consisted of individuals on a waiting list for the next hospice training program, and an experimental group, which consisted of individuals who were beginning the hospice training program. The Collett-Lester Fear of Death Scale was used in a pre-test, training, post-test, and then follow-up test design. The training included a class on practical skills pertaining to the needs of the terminally ill and aspects of death and dying. The results of Werner's study clearly indicate that volunteers who participated in the hospice training program were more comfortable with those who were dying and the families' needs when compared to the group that did not receive the training in death and dying. Interestingly, no significant differences were found between the post-test and follow-up test, though significant differences did occur between the pre-test and post-test in measuring their fear of death and death awareness on the individuals who received education on death and dying.

Other research on death anxiety and awareness was conducted on individuals not involved in hospice, but offers interesting results pertaining to attitudes of death and dying. Triplett et al. (1995) chose a group of 280 undergraduate college students to explore participants' levels of death of self, death of others, dying of self, and dying of others using the Collett-Lester Fear of Death Scale. In addition to exploring issues of death and dying the researchers wanted to see whether there was a correlation between religious attachment and coping with death and dying. Overall, the results indicate that low levels of fear of death and dying of self and others are associated with a strong attachment to a religious belief. Persons with a strong attachment to their religious conviction had lower levels in death anxiety, but the researchers stated that more research is needed to make a conclusive statement that low death anxiety is a result of religious attachment.

Fear of death and attitudes on aging were examined by Davis-Berman (1998) using a group of fifty-six undergraduate students who enrolled in either a course on aging or a course on death and dying. Measurements were taken at the beginning and end of the semester to compare whether course information affected their attitudes on aging and death and dying. The Leming Fear of Death Scale, originally developed especially for researching fear of death in undergraduate students, was administered. Attitudes on aging were measured using a Likert-type scale developed by the researchers. Both classes decreased significantly in their death anxiety. In the aging class, attitudes on aging significantly improved after completing the semester, but the students in the death and dying class experienced no attitude changes from the beginning to the end of the

course semester. The researchers concluded that it would be advantageous to have more college courses that focus on the normal process of aging.

In a similar study, Gomez, Young and Gomez (1991) explored attitudes toward the elderly and fear of death using eighty-six senior college nursing students. Fear of death was assessed using the Collett-Lester Fear of Death Scale, and attitudes toward the elderly was assessed using Kogan's Attitude Toward Old People Scale. The researchers only administered the measures once *after* an upper division nursing course during the last semester. The researchers state that there is previous research that claims that high anxiety toward death correlates with positive attitudes toward the elderly, but their results showed no significant relationship between the two. The results did indicate that those senior college nursing students who had previous experience living or caring for an elderly person had a higher preference for working with the elderly.

Gomez et al. (1991) also found a positive influence between the degree of religious experience or beliefs and whether or not they would work with the elderly population in the future. Additional research has further explored this issue. In a study focusing on childhood religion and hospice it was found that childhood religion was an influential element in choosing to be involved in hospice work. However, high religiosity was not found to be a significant factor in level of comfort when dealing with dying (Mason, 1995). Interestingly, all of the hospice volunteers in Uffman's (1993) study stated they were Christians and believed in life after death. Briggs (1987) surveyed 166 hospice volunteers and asked their reasons for becoming hospice volunteers. The results show that their religious beliefs were the second most important reason for becoming a hospice volunteer. In the same study volunteer qualities were rated and the

second most important quality was respect for religious beliefs other than one's own (Briggs, 1987). It is evident that the rewards of hospice work offer a sense of heightened meaning and personal growth for the individuals involved, and this often involves aspects of spiritual or religious beliefs (Vachon, 1987; Wentzel, 1981).

In summary, it is not surprising that hospice volunteers score low in death anxiety and high in their ability to cope with those that are dying. Often, the hospice volunteers have confronted their own mortality and are generally more self-actualized. Hospice volunteers also seem better able to deal with the uncontrollability of death and dying. It has been suggested by several studies that the training the hospice volunteers receive has much to do with their ability to cope with death and dying. Death education and awareness are important components to most training programs and help the hopeful volunteers clearly understand what their hospice responsibilities will entail. Clearly, most hospice volunteers are able to successfully cope with the all-encompassing issues pertaining to death and dying for a myriad of reasons, but most important are reasons of compassion toward the terminally ill and their families.

### Purpose of Study

The present study will examine specific characteristics of hospice volunteers in the state of Maine. These characteristics include their motivations for becoming a hospice volunteer and attitudes on death and dying. In addition, religious and spiritual beliefs will be explored to find out whether religious beliefs help hospice volunteers cope with issues of death and dying. This study is an extension of similar studies conducted outside of Maine. Specifically, the following questions were investigated:

## Research Questions

- Question 1: What are Maine hospice volunteers' motivations for participating in hospice work?
- Question 2: What level of death anxiety do Maine hospice volunteers report, and how does this compare with results from past studies done outside the state of Maine?
- Question 3: Is the level of death anxiety correlated with the following: age, sex, education, number of families assigned in the last year, number of support meetings attended in the last year, and number of educational workshops attended in the last year?
- Hypothesis 1: A greater number of hospice volunteer years is associated with lower levels of death anxiety.
- Question 4: Are religious and spiritual beliefs associated with individuals' obligation to become a hospice volunteer in the state of Maine?
- Question 5: Are religious and spiritual beliefs associated with Maine hospice volunteers' ability to cope with death and dying?

## Chapter II

### Methods

#### Sample and Procedure

Participants for this research project were volunteers from Maine hospice programs statewide registered under the Maine Hospice Council (see Appendix C for a list of participating hospice programs). The Maine Hospice Council is designed to provide information to the public about the availability of hospice care in the state of Maine. The researcher contacted the volunteer coordinator in each of the hospice programs and arrangements were made for the researcher to travel to each individual hospice program and supply them with the appropriate number of survey packets.

Each packet consisted of a cover letter, a survey, and a stamped return envelope addressed to the researcher. Packets were sealed in blank stamped envelopes so that each hospice program could label them to be sent to each individual hospice volunteer. Approximately two months after the distribution of the survey packets to each Maine hospice program, the researcher contacted each program again to verify if there were any survey packets not sent out to their hospice volunteers. This procedure allowed the researcher to know the actual number of survey packets mailed to Maine hospice volunteers.

In total, 1,058 survey packets were distributed and 701 were completed and returned, a 74% return rate. There were 573 (82%) female respondents and 128 (18%) male respondents. The ages of the respondents ranged from 21 to 85 (Mean = 57), with

76% between the ages of 40 and 69 (Table 1). Most of the respondents (96%) were White, non-Hispanic, and 3% were Native American.

Most respondents had some higher education beyond high school: 26% had some college experience, 36% had a college degree, and 23% had a graduate degree. Overall, 85% of the respondents had some college experience or beyond.

### Instrument

The survey consisted of a cover letter, survey questions pertaining to the motivations of hospice volunteers (Black & Kovacs, 1999), the Collett-Lester Fear of Death and Dying Scale (Revised Version) (as cited in Gomez et al., 1991; Hayslip & Walling, 1985-86; Lester, 1994; Triplett et al., 1995; Werner, 1990), demographics, and questions asking about their hospice volunteer involvement. The cover letter (Appendix A) explained that participation in this study was voluntary and questions could be skipped if participants did not want to answer them. The cover letter also instructed participants not to put their name on the survey in order to ensure anonymity.

The first twelve survey questions that examine the motivations of the hospice volunteer (see Appendix B) were directed toward Question #1 in the Purpose of Study. These questions, which examine twelve specific motivations for volunteering to participate in hospice, were developed by Black and Kovacs (1999). For example, one motivation reason reads, "I wanted to help persons in need." The respondent indicated the degree to which this reason defined their motivation for volunteering for hospice on a scale ranging from "No Influence" (score of 0) to "Very High Influence" (score of 4).

Table 1

**Demographic Characteristics of Respondents (n = 701)**

	<u>n</u>	<u>%</u>
<b>Sex</b>		
Female	573	81.7
Male	128	18.3
<b>Age</b>		
20 – 29	10	1.4
30 – 39	50	7.1
40 – 49	123	17.5
50 – 59	237	33.9
60 – 69	174	24.8
70 – 79	94	13.4
80 – 89	13	1.9
<b>Race / ethnicity</b>		
Asian, Pacific Islander	1	.1
Hispanic	3	.4
White, non-Hispanic	673	96.0
Native American	<b>24</b>	3.4
<b>Education</b>		
Less than high school	7	1.0
High school diploma	105	15.0
Some college	181	25.8
College degree	249	35.5
Master's degree	130	18.5
Doctoral degree	28	4.0
Other degree or education	1	.1
<b>Volunteer community</b>		
Remote / rural community	127	18.1
Small town	347	49.5
Small / medium city	187	26.7
Suburb	19	2.7
Large city	21	3.0

A question designed by the researcher asking about religious and spiritual beliefs was developed to determine if these beliefs influenced respondents' ability to cope with issues related to death and dying (question 13, Appendix B).

The Collett-Lester Fear of Death and Dying Scale (Revised Version) (Appendix B) was used to measure participants' self-reported death anxiety in four domains: death of self, dying of self, death of others, and dying of others (Lester, 1999). Each question (14-45) was designed on a Likert style 5-point scale. The following are examples of the four subscale categories examining participants' death anxiety. In the category of Fear of Your Own Death *one* of the eight statements reads, "Missing out on so much after you die"; in the category Fear of Your Own Dying one of the eight statements reads, "The intellectual degeneration of old age"; in the category Fear of the Death of Others one of the eight statements reads, "Losing someone close to you"; and in the category Fear of the Dying of Others one of the eight statements reads, "Having to be with someone who is dying". Participants indicated how anxious they were in regard to the experience described in each statement on a scale of 1 (not anxious) to 5 (very anxious).

In the demographic section of the survey (see Appendix B) participants provided information about their age (question 46), sex (question 47), racial or ethnic group (question 48), number of years of education completed (question 49), number of years as a hospice volunteer (question 50), type of involvement in hospice (questions 51-53), and type of community in which they generally conducted their hospice volunteering (question 54).

The last page of the survey gave the participant the opportunity to further comment on any aspect of their hospice volunteer work and experience with an open-ended question.

### Data Analysis

The revised Collett-Lester Fear of Death and Dying Scale (CLFDD) was scored for each respondent by assigning numerical values to each Likert style 5-point response from “Not Anxious” (score of 1) to “Very Anxious” (score of 5), and summing the values for items in each subscale. The total possible score for each subscale ranged from 8 (very low anxiety) to 40 (very high anxiety).

Analyses were performed utilizing the **SPSS** statistical software. Correlations were calculated between the four CLFDD subscales and respondents’ age, education level, number of families assigned in the last year, number of support meetings attended in the last year, and number of educational workshops attended in the last year. Mean differences between the sexes for each of the CLFDD subscales were calculated using independent t-tests.

The influence of religious and spiritual obligation on becoming a hospice volunteer, whether religious and spiritual beliefs were associated with the hospice volunteers’ ability to cope with issues of death and dying, and demographic characteristics were assessed using frequency distributions.

## Chapter III

### Results

#### Volunteer Activity

As shown in Table 2, 68% of the participants volunteered for hospice for one to five years. A majority, 69% of the hospice volunteers cared for one to four families in the last year, and 16% of the hospice volunteers had not cared for any hospice families in the last year. Fifty percent attended one to six hospice volunteer support meeting in the last year, and 34% chose not to attend hospice volunteer support meetings. Interestingly, these hospice volunteers attended more educational workshops when compared to support meetings ;73% attended one to six workshops in the last year (Table 2).

#### Question 1

Question 1 examined the motivations of the participants to be a hospice volunteer (Table 3). Motivation scores ranged from “No Influence” (score of 0) to “Very High Influence” (score of 4). The motivations with the highest mean influence scores were, “I wanted to help persons in need” ( $M = 3.55$ ,  $SD = 0.80$ ), “I wanted to ease the pain of those in hospice programs” ( $M = 2.90$ ,  $SD = 1.33$ ), “I have a unique expertise to contribute that the program needs” ( $M = 1.80$ ,  $SD = 1.51$ ), and “I wanted to fulfill a civic responsibility” ( $M = 1.42$ ,  $SD = 1.38$ )(Table 3).

Table 2

**Volunteer Activity of Respondents (n = 701)**

	<u>n</u>	<u>%</u>
Total volunteer years		
1 – 5 years	475	67.8
6 – 10 years	139	19.8
11 – 15 years	55	7.8
16 – 20 years	28	4.0
over 20 years	4	.6
Number of families assigned in the last year		
None	111	15.8
1 – 2 families	308	43.9
3 – 4 families	177	25.2
5 – 6 families	56	8.0
7 – 8 families	15	2.1
9 – 10 families	13	1.8
11 – 15 families	17	2.4
over 15 families	4	.6
Number of support meetings attended in last year		
None	238	34.0
1 – 2 support meetings	188	26.8
3 – 4 support meetings	109	15.5
5 – 6 support meetings	53	7.6
7 – 8 support meetings	28	4.0
9 – 10 support meetings	50	7.1
11 – 12 support meetings	25	3.6
over 12 support meetings	10	1.4
Number of educational workshops attended in last year		
None	141	20.1
1 – 2 workshops	303	43.2
3 – 4 workshops	162	23.1
5 – 6 workshops	47	6.7
7 – 8 workshops	16	2.3
9 – 10 workshops	18	2.6
11 – 12 workshops	11	1.6
over 12 workshops	3	.4

Table 3

**Volunteer Motivation Mean Scores**

Why did you become a Hospice Volunteer?	<b>M</b>	<b>SD</b>
I wanted to help persons in need.	3.55	0.80
I wanted to ease the pain of those in hospice programs.	2.90	1.33
I have a unique expertise to contribute that the program needs.	1.80	1.51
I wanted to fulfill a civic responsibility.	1.42	1.38
I wanted to fulfill a religious obligation.	1.05	1.39
I wanted to gain work or educational experience.	1.05	1.44
I have a friend volunteering in a hospice program.	0.82	<b>1.33</b>
I have had a relative in a hospice program.	0.81	1.49
I heard from a friend that volunteering was a good experience.	0.72	1.25
I have been helped by a volunteer in the past and wanted to give something back.	0.71	1.37
I was seeking personal support.	0.57	1.01
I had a research interest in this area.	0.50	1.06

Note. Motivation scores ranged from 0 (no influence) to 4 (very high influence). Volunteer motivations are listed in rank order from highest to lowest mean scores.

### Question 2

Question 2 addressed level of death anxiety in hospice volunteers. A measure of internal consistency, Cronbach's coefficient alpha, was calculated for each of the four Collett-Lester Fear of Death and Dying (CLFDD) subscales. It was found that levels of internal consistency were satisfactory: .79 for the Your Own Death subscale, .85 for the Your Own Dying subscale, .77 for the Death of Others subscale, and .80 for the Dying of Others subscale.

Death anxiety scores ranged from 8 to 30 in the Fear of Your Own Death subscale ( $\underline{M} = 15.62, \underline{SD} = 6.00$ ), 8 to 32 in the Fear of Your Own Dying subscale ( $\underline{M} = 24.83, \underline{SD} = 6.98$ ), 8 to 27 in the Fear of Others Death subscale ( $\underline{M} = 20.78, \underline{SD} = 5.58$ ), and 8 to 27 in the Fear of Others Dying subscale ( $\underline{M} = 19.89, \underline{SD} = 5.47$ ) (Table 4). Since lower scores indicate lower anxiety the results indicate that, for this sample, one's own death was the least anxiety-producing and one's own dying was associated with the most anxiety.

### Question 3

Question 3 examined the relationship between the four CLFDD subscales and sex, age, education, number of family members cared for, number of support meetings attended in last year, and number of educational workshops attended in last year.

Mean sex differences for the four CLFDD subscales were examined using independent t-tests (Table 4). Although the mean differences were relatively small, females scored significantly higher than males on all four death anxiety subscales.

Table 4

## Mean Death Anxiety Subscale Scores by Sex

Death anxiety subscale	Overall		Female (n=573)		Male (n=128)		t
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	M	S D	
Your own death	15.62	(6.00)	15.87	(6.10)	14.46	(5.07)	2.44*
Your own dying	24.83	(6.98)	25.31	(6.96)	22.67	(6.70)	3.90*
Death of others	20.78	(5.58)	20.94	(5.63)	20.08	(5.30)	1.57*
Dying of others	19.89	(5.47)	20.04	(5.54)	19.23	(5.10)	1.52*

Note. Possible death anxiety subscale scores range from 8 (not at all anxious) to 40 (very anxious).

\*  $p < .05$

Pearson correlations between the death anxiety subscales and selected variables are presented in Table 5. Age was a significant predictor of three of the death anxiety subscales, with the strongest relationship between age and anxiety regarding one's own death ( $r = -.25, p < .01$ ). That is, being older was associated with lower levels of anxiety concerning one's own death. A higher educational level was associated with lower levels of anxiety regarding others' dying ( $r = -.10, p < .01$ ), but education was not significantly correlated with the other subscales. The greater number of families respondents had been assigned to ( $r = -.12, p < .01$ ) and the more educational workshops they had attended ( $r = -.10, p < .01$ ), the lower their level of anxiety over others' dying. It should be noted that the magnitude of even the significant correlations is quite small. In no case does the selected variable account for more than six percent of the variance in a death anxiety subscale.

### Hypothesis 1

It was hypothesized that there would be lower levels of death anxiety among respondents who had more years of volunteer experience. Significant correlations occurred for three of the four CLFDD subscales. The more years the respondent volunteered for hospice, the lower the anxiety about their own death ( $r = -.10, p < .05$ ), the lower the anxiety about others death ( $r = -.08, p < .05$ ), and the lower the anxiety about others' dying ( $r = -.09, p < .05$ ) (Table 5).

Table 5

**Pearson Correlations Between Death Anxiety Subscales and Predictor Variables**

	Your Death	Your Dying	Others Death	Others Dying
Age	-.25**	-.08*	.09*	-.02
Education level	-.05	.01	-.04	-.10**
Years volunteered	-.10*	.01	-.08*	-.09*
Families assigned in last year	-.03	-.02	-.02	-.12**
Support meetings attended in last year.	-.08*	-.01	-.01	-.03
Educational workshops attended in last year.	-.00	.01	-.04	-.10**

\* =  $p < .05$

\*\* =  $p < .01$

#### Question 4

Are religious and spiritual beliefs associated with individuals' obligation to become a hospice volunteer in the state of Maine? As indicated in Table 6, a majority (57%) of the respondents reported that fulfilling a religious obligation had no influence on their volunteering for hospice. Approximately 19% said that it had high or very high influence, and 24% said that it had low or some influence.

#### Question 5

Question 5 asked whether religious and spiritual beliefs were associated with the hospice volunteers' ability to cope with aspects of death and dying involved in the volunteer capacity. Approximately 64% of the respondents stated that their religious and spiritual beliefs highly or very highly influenced their ability to cope with issues of death and dying. About 19% stated that their religious and spiritual beliefs somewhat influenced their ability to cope, and 17% stated no influence at all (Table 7).

#### Responses to the Open-Ended Item

From the 701 surveys, 376 (54%) of the respondents offered comments that further elaborated on their hospice volunteer experience. Preliminary analysis of the respondent's comments indicated five main themes. From the 376 comments, 23% of the respondents stated that hospice volunteer work allowed them the opportunity to "give back" either from a past death experience of a loved one through a hospice program, or because there were no hospice programs available from a past death experience of a

Table 6

**Are Religious and Spiritual Beliefs Associated with Individuals'  
Obligation to Volunteer for Hospice? (n = 701)**

	<u>n</u>	<u>%</u>
Very high influence	66	9.4
High influence	68	9.7
Some influence	100	14.3
Low influence	69	9.8
No influence	398	56.8

Table 7

**Are Religious and Spiritual Beliefs Associated with Individuals'  
Ability to Cope with Issues of Death and Dying? (n = 701)**

	<u>n</u>	<u>%</u>
Very high influence	277	39.5
High influence	174	24.8
Some influence	97	13.8
Low influence	36	5.1
No influence	117	16.7

loved one and they wished there had been. For example, the following are a selection of comments received in the survey that elaborate on the theme of “giving back” because of past experience:

Initially I was trying to “give back” for the help and support I myself received after my first husband’s death.

As a disabled Vietnam Veteran, I saw a number of people die in the field, most not even in a hospital situation and without family members or close friends around. I believe I decided at that time that if I ever had the chance to be supportive in a death at home that I would be involved.

My reason for becoming a hospice volunteer was because I had two parents die within two years of each other, both of long hard cancer death and no one was available in the area to help support them or myself.

The most rewarding part of my nursing career occurred after my retirement, caring for the terminally ill and dying person. Hospice became a continuation of my nursing career, which I truly loved.

Nine percent stated that they felt hospice volunteer work was religiously or spiritually beneficial for them and that they were influenced in some way due to their religious and spiritual beliefs. Several comments indicated that they had a “special calling” to volunteer for hospice, and grateful that they can be of help to the terminally ill and their families and loved ones during this period of time.

The hospice volunteer training program is a wonderful emotional and spiritual experience.

I’m just beginning my hospice volunteer work and feel as though I am on an educational and spiritual journey.

Hospice volunteering has provided me with much spiritual growth.

Hospice volunteering has been a wonderful growth experience; mentally, emotionally and spiritually.

Another 9% of the respondents commented on their positive feelings about the hospice program and the hospice philosophy. Many were grateful to be a part of the hospice team and helping those in their communities.

Hospice is a wonderful program to be involved in.

There is no doubt that hospice care is the best possible care for the terminally ill and I will devote myself to serving with whatever provided practice in my community, raise money, and advocate everywhere!

I am very blessed to be able to work with hospice.

I think hospice is a wonderful organization and I appreciate it very much in what it does and what it stands for.

Thirty percent of the respondents mentioned the rewards of being a hospice volunteer, often unexpectedly, indicating that they felt they were receiving more than they were giving.

Being a hospice volunteer has caused me to become much more understanding of life and death. I am a better person.

Working as a hospice volunteer is one of the most rewarding things you can do with your life. When I leave the home and head back to my own home everything seems clearer. You understand your own purpose and little things don't seem so big anymore. And knowing you're giving comfort to the patient and their families fill your whole soul.

I believe I always receive much more than I give.

Thirty-two percent of the respondents who wrote comments clearly stated that their feeling and attitudes about death and dying were affected by their hospice experience. Some stated that they were "no longer afraid" of the dying process, and some stated that it was an honor and a privilege to be involved in hospice and caring for the needs of the terminally ill, their family and friends during this often difficult time.

Hospice has given me the tools to better understand the process of dying.

I am very comfortable with death and dying.

It is an honor and a privilege to be included in a family at these intimate moments. I have learned so much from the dying as to what is really important.

Overall, many of the respondents reported that they felt fortunate to be a hospice volunteer, that they had grown as an individual because of the experience, and that their lives outside of the volunteering had been positively affected due to their hospice volunteer work (see further comments in Appendix D).

## Chapter IV

### Discussion

Clearly, Maine hospice volunteers are strong advocates for the hospice philosophy and meeting the needs of the terminally ill and their families and friends. This is supported by the relatively high response rate of 74%.

Question 1 explored the motivations of Maine hospice volunteers who participate in hospice work. Past research on motivations of hospice volunteers concluded that a majority of hospice volunteers' were motivated with the desire to help others in need, the opportunity to give back to others, and for personal growth (Black & Kovacs, 1999; Hall & Marshall, 1996; Patchner & Finn, 1987). Other past research found that what motivated many hospice volunteers was the need to learn more about the dying process and the mortality of life (Wentzel, 1981). The results of these survey studies clearly illustrate that a majority of the hospice volunteers wanted to help others in need, especially those in hospice programs, and become knowledgeable about the physical, emotional and spiritual needs of those dying. Previous personal experience with hospice care was another motivation found in past research (Uffman, 1993; Vachon, 1987; Wentzel, 1981). In the present study, many of the respondents reported that they had personally experienced the care that hospice provides because of the death of a loved one or family member and wanted to give back to others. Other respondents stated that they wished hospice care would have been available to a loved one or family member and had not been, and because of this they desired to become active as a hospice volunteer to help provide for others in need.

Question 2 examined whether Maine hospice volunteers report similar levels of death anxiety when compared to previous research. In previous studies conducted outside the state of Maine (Amenta, 1984; Robbins, 1991, 1992), hospice volunteers generally demonstrated low levels of death anxiety and high levels of death awareness. The results of the present research clearly mirror these findings. This finding is no doubt due, at least in part, to the selection process of hospice programs for their volunteers and the death education received during hospice training. Often, when someone is overly anxious about issues of death and dying, they quickly become aware of it during their hospice training and therefore choose not to complete the training program. It is also probable that people with high levels of death anxiety are unlikely to volunteer for hospice work.

Each hospice program trains hospice volunteers slightly differently, but overall the core issues of death and dying, and how that affects them and those they are caring for, are foremost in the hospice volunteer training process. This is because hospice programs want to inform and educate their hospice volunteer trainees so that they can best attend to the needs of the individual in need of hospice care, their families and friends.

In examining Question 3, the results indicate moderate age differences in death anxiety with older respondents having somewhat lower levels. It might be plausibly argued that this supports the belief that age decreases some individuals' anxiety because of increased familiarity with death-related experiences, including the experience of hospice. However, the results may also simply represent anxiety differences among different age cohorts. In other words, these results remind us that cross-sectional studies

confound age differences with age changes and do not allow us to draw definite conclusions about which of these is most in evidence. A longitudinal study would be necessary to further address this issue.

The levels of death anxiety in all four CLFDD subscales were slightly different between the male and female population in this study, with females showing more anxiety overall compared to males. Though, these differences are relatively small it causes one to consider what factors contribute to these differences. For example, are females more prone to express their anxiety compared to males?

The results also suggest that a lower level of anxiety over others' dying is associated with higher educational attainment, a greater number of educational workshops attended, and a greater number of families served during the last year. However, the correlations are quite low, suggesting that the association is not particularly strong.

A testing of Hypothesis 1 showed a significant correlation between number of years as a hospice volunteer and lower levels of death anxiety. Understandably, the more years one has volunteered for hospice, the more likely one has confronted the death of many individuals, either by being there with the patient at the time of their death or not. **If** an individual hospice volunteer is struggling from the death and dying of an assigned hospice patient, they often become aware that they are not adequately equipped to further volunteer at that time.

Often, hospice volunteers are required to take "time off" between hospice patients' deaths so that they can effectively grieve the loss. This helps to reassure the hospice volunteer and the program they volunteer for that they are emotionally,

physically and spiritually ready to help the next assigned hospice patient. Effective communication between the hospice volunteer and the program they volunteer for is essential, not only for the well being of the hospice volunteer, but also for the hospice patient, families and friends the hospice programs provides services for.

Question 4 explored whether religious and spiritual beliefs were associated with the individuals' obligation to become a hospice volunteer. Overall, a majority of the respondents said that religious obligations did not influence their decision to volunteer for hospice. It is important to note that survey comments referred to some aspect of religion or spiritual beliefs that enabled them to continue their hospice volunteer work. Though few stated that their religious or spiritual beliefs obligated them to serve a hospice program, many mentioned that their beliefs somehow gave them the guidance needed to conduct their hospice volunteer work well. The manner in which the survey question was worded, i.e., "to fulfill a religious obligation" (emphasis added), may have affected the results. Spiritual issues may have influenced some respondents' decision to volunteer, but they may not have felt such beliefs obligated them to do so.

In contrast, many Maine hospice volunteers stated that their religious and spiritual beliefs helped in their ability to cope with the many issues of death and dying that arise in their hospice volunteer work (Question 5). This message was quite clear in the many survey comments received that indicated that if it weren't for their beliefs, they would not be able to hospice volunteer. Some stated that they strongly believed in some form of life after death, which allowed them to be near those who were dying and cope with the death of those in the future. Past research found similar results that religious beliefs and the

belief in life after death play a strong role in their experience as a hospice volunteer and caring for those who are dying (Briggs, 1987; Uffinan, 1993).

Other issues to consider from the results of this survey study are the percentage of Maine hospice volunteers that did not attend any support meetings in the last year (34%), and the percentage that did not attend any educational workshops in the last year (20%). Even though the percentages in these two categories seem relatively high, it is important to consider possible reasons. One plausible reason may be the remoteness of many Maine communities that may make it difficult for some hospice volunteers to travel, sometimes long distances, to these meetings and workshops. Another possible factor may be the times in which the support meetings and educational workshops are offered that may conflict with family and career obligations. Each hospice program designs and provides their support meetings and educational workshops differently, and the reasons hospice volunteers cannot, or choose not to attend such events vary.

Some respondents volunteered what their profession or career was when they indicated their number of years of education completed. Not surprisingly many of these respondents (15%) shared that they were either actively involved in the medical field (CNA, RN, LPN, EMT, PCA, PA, MD, Med Tech, etc.), or were retired from these professions and found it enjoyable to now have the time to spend with patients without having to attend to other duties. Others simply felt they had the appropriate skills to attend to the needs of the dying. Job training and experience thus seems to have an influence on who chooses to be involved in hospice volunteering.

### Study Limitations

Though the return rate was high in this survey study (74%), there were still many surveys not completed and returned. It is important to consider the possibility that a portion of the 26% non-returns were volunteers who were more anxious about issues of death and dying, and filling out the survey would have been emotionally troubling. In other words, it is possible that some of the attitudes and characteristics of respondents were different from those who didn't respond. Therefore one needs to be cautious in attempting to generalize to the hospice volunteer populations as a whole.

In addition, the respondents in this survey study were primarily White (96%). Therefore, the reader should be careful not to generalize to other racial and ethnic populations until further research is conducted.

### Implications for Future Research

Although this research adds to the growing number of studies pertaining to issues of hospice volunteer retainment, training, and support, it does not exhaust possibilities for future research. Issues pertaining to the profession and career of the hospice volunteer could be further elaborated, particularly pertaining to those involved in medical and religion-based professions. Those with little or no education beyond high school would be an interesting population to research, since it is clear that they are not often studied.

Though quantitative research offers invaluable insight about hospice care and its volunteers, it would be advantageous to conduct interview research with hospice volunteers about more specific issues pertaining to their volunteer work. This type of

approach might be valuable in probing for the reasons underlying some of the findings presented here.

Research conducted on death anxiety and awareness provides potentially valuable information to hospice programs and the volunteer themselves. In this vein, it would be useful to assess volunteers' level of death anxiety and awareness prior to training and after training is completed. This would help to determine whether changes occur as a result of education about death and dying conducted during the hospice volunteer training process.

## REFERENCES

Amenta, M. M. (1984). Death anxiety, purpose in life and duration of service in hospice volunteers. Psychological Reports, 54, 979-984.

Ballo, J. K. (1991). Hospice volunteers: A priceless commodity. Free Inquiry, Winter 1992, 12, 18-28.

Beresford, L. (1993). The hospice handbook: A complete guide. Boston: Little, Brown and Company.

Black, B., & Kovacs, P. J. (1999). Age-related variation in roles performed by hospice volunteers. The Journal of Applied Gerontology, 18(4), 479-497.

Briggs, J. S. (1987). Volunteer qualities: A survey of hospice volunteers. Hospice & Palliative Care, 14(1), 27-31.

Burnell, G. M. (1993). Final choices: To live or to die in an age of medical technology. New York: Insight Books – Plenum Press.

Cox, M. S. (1979). The Connecticut hospice volunteer program. In M. P. Hamilton & H. F. Reid (Eds.), A new way to care for the dying: A hospice handbook (pp. 157-172). Grand Rapids: William B. Eerdman's Publishing Company.

Cunningham, W. R., & Brookbank, J. W. (1988). Gerontology: The psychology, biology, and sociology of aging. New York: Harper & Row, Publishers.

Davis-Berman, J. (1998). Attitudes toward aging and death anxiety: Aging and death class. Omega, 38(1), 59-64.

DuBois, P. M. (1980). The hospice way of death. New York: Human Sciences Press.

Finn-Paradis, L., & Usui, W. M. (1987). Hospice volunteers: The impact of personality characteristics on retention and job performance. The Hospice Journal, 3(1), 3-30.

Finn-Paradis, L., Miller, B., & Runnion, V. M. (1987). Volunteer stress and burnout: Issues for administrators. The Hospice Journal, 3(2), 165-183.

Frankl, V. E. (1959). Man's search for meaning: An introduction to logotherapy. Boston: Beacon Press.

Glass, J. C., & Hastings, J. L. (1992). Stress and burnout: Concerns for the hospice volunteer. Educational Gerontology, 18, 715-731.

Gomez, G. E., Young, E. A., & Gomez, E. A. (1991). Attitude toward the elderly, fear of death, and work preference of baccalaureate nursing students. Gerontology & Geriatrics Education, 11(4), 45-56.

Hall, S. E., & Marshall, K. (1996). Enhancing volunteer effectiveness. The American Journal of Hospice & Palliative Care, 13(3), 22-25.

Hayslip, B., & Walling, M. L. (1985-86). Impact of hospice volunteer training on death anxiety and locus of control. Omega, 16(3), 243-254.

Hospice of St. Joseph. (1997). Hospice volunteer training manual. Maine: St. Joseph Healthcare.

Kavanagh, E. (1983). Volunteers in hospice. In C. A. Corr, & D. M. Corr. (Eds.), Hospice care: Principles and practice (pp. 209 –222). New York: Springer Publishing Company.

Lafer, B. (1991). The attrition of hospice volunteers. Omega, 23(3), 161-168.

Laliberte, L., & Mor, V. (1988). The hospice volunteer. In V. Mor, D. S. Greer, & R. Kastenbaum. (Eds.), The hospice experiment (pp. 187-208). Baltimore: The Johns Hopkins University Press.

Lester, D. (1994). The Collett-Lester Fear of Death Scale. In R. A. Neimeyer (Ed.), Death anxiety handbook: Research, instrumentation, and application (pp. 45-60). Washington DC: Taylor & Francis Publishers.

Mason, B. A. (1995). The hospice volunteer and childhood religion (Doctoral dissertation, California State University, Long Beach, 1995). UMI ProQuest Digital Dissertations.

Mitchell, C. W., & Shuff, I. M. (1995). Personality characteristics of hospice volunteers as measured by Myers-Briggs Type Indicator. Journal of Personality Assessment, 65(3), 521-532.

Mor, V. (1987). Hospice care systems: Structure, process, costs, and outcome. New York: Springer Publishing Company.

Morgan, J. D. (1995). Living our dying and our grieving: Historical and cultural attitudes. In H. Wass & R. A. Neimeyer (Eds.), Dying: Facing the facts (pp. 25-45). Washington DC: Taylor & Francis Publishers.

Munley, A. (1983). The hospice alternative: A new context for death and dying. New York: Basic Books, Inc., Publishers.

- Murrant, G., & Strathdee, S. A. (1995). Motivations for service volunteers involvement at Casey House Aids Hospice. The Hospice Journal, 10(3), 27-38.
- National Association for Home Care. (1999). [www.nahc.org](http://www.nahc.org).
- National Hospice and Palliative Care Organization. (1999).
- Patchner, M. A., & Finn, M. B. (1987). Volunteers: The life-line of hospice. Omega, 18(2), 135-144.
- Robbins, R. A. (1991). Death anxiety, death competency and self-actualization in hospice volunteers. The Hospice Journal, 7(4), 29-35.
- Robbins, R. A. (1992). Death competency: A study of hospice volunteers. Death Studies, 16, 557-569.
- Sadler, C., & Marty, F. (1998). Socialization of hospice volunteers: Members of the family. The Hospice Journal, 13(3), 49-68.
- Scott, J. P., & Caldwell, J. (1996). Needs and program strengths: Perceptions of hospice volunteers. The Hospice Journal, 11(1), 19-30.
- Siebold, C. (1992). The hospice movement: Easing death's pains. New York: Twayne Publishers.
- Siegel, B. S. (1986). Love, medicine & miracles: Lessons learned about self-healing from a surgeon's experience with exceptional patients. New York: Harper & Row.
- Stephany, T. (1984). Identifying roles of hospice volunteers. Home Healthcare Nurse, 7(3), 51-52.
- Tamlyn, D. L., & Caty, S. (1985). Hospice volunteers' attitudes toward death: Effects of education. Dimensions Health Service, 62(6), 37-8.
- Tomer, A. (1994). Death anxiety in adult life: Theoretical perspectives. In R.A. Neimeyer (Ed.). Death anxiety handbook: Research, instrumentation and application (pp. 3-28). Washington DC: Taylor & Francis Publishers.
- Triplett, G., Cohen, D., Reimer, W., Rinaldi, S., Hill, C., Roshdieh, S., Stanczak, E. M., Siscoe, K., & Templer, D. I. (1995). Death discomfort differential. Omega, 31(4), 295-304.
- Uffman, B. (1993). Living with dying: A qualitative study of hospice volunteers (Doctoral dissertation, California Institute of Integral Studies, 1993). UMI Dissertation Abstracts, 9333550.

Vachon, M. L. S. (1987). Occupational stress in the care of the critically ill, the dying, and the bereaved. Washington: Hemisphere Publishing Corporation.

Wentzel, K. B. (1981). To those who need it most, hospice means hope. Boston: Charles River Books.

Werner, J. S. (1990). The effect of death education training upon fear of death among hospice volunteers (Doctoral dissertation, Adelphi University, School of Social Work, 1993). UMI Dissertation Abstracts, 9022335.

Wilkinson, H. J., & Wilkinson, J. W. (1986-87). Evaluation of a hospice volunteer training program. Omega, 17(3), 263-275.

**APPENDIX A**  
**Informed Consent Sheet**

Dear Participant,

My name is Anne Donovan, and I am a graduate student in Human Development at the University of Maine. I have also been an active hospice volunteer for three years. In partial fulfillment of my degree requirements, I am conducting a survey study of motivations for becoming a hospice volunteer and ideas about death and dying, and I am requesting your participation.

Participation in this study is completely voluntary and you are under no obligation to participate if you do not wish to do so. You have the right to withdraw from participation at any time, and you do not have to answer any questions that you do not want to. Responses to this survey are strictly anonymous. If the results of this survey are published, no names will be used and there will be no way responses can be traced to you.

If you do wish to participate, please fill out the survey, which takes approximately 15 minutes. Answer each question to the best of your ability and return it in the stamped return envelope provided. Please do not put your name on the survey.

Participation in this survey will provide you with an opportunity to look at your own experiences and issues as they relate to your hospice volunteer work. In addition, this research will add to the growing number of studies being conducted about hospice work and how it impacts families and friends in our communities.

If you have any questions or concerns about this survey, or would like a copy of the results upon completion of the study, please feel free to call me at (207)-581-3126 or contact my thesis advisor, Dr. Marc Baranowski at (207)-581-3122. You may also call long distance (toll free) at 1-888-275-2530 or email me at [anne\\_\\_donovan@umit.maine.edu](mailto:anne__donovan@umit.maine.edu). Thank you in advance for your time and participation.

Sincerely,

Anne Donovan  
Graduate Student

## APPENDIX B

### MAINE HOSPICE VOLUNTEER SURVEY

Questions 1-13. Why did you become a hospice volunteer? Please indicate how much each of the following reasons influenced your decision to volunteer by circling the one most appropriate response beside each possible reason.

Reasons	no influence	1	some influence	2	3	very high influence	4
1. I was seeking personal support.	0	1	2	3	4		
2. I wanted to help persons in need.	0	1	2	3	4		
3. I have a friend volunteering in a hospice program.	0	1	2	3	4		
4. I had a research interest in this area.	0	1	2	3	4		
5. I wanted to gain work or educational experience.	0	1	2	3	4		
6. I have had a relative in a hospice program.	0	1	2	3	4		
7. I heard from a friend that volunteering was a good experience.	0	1	2	3	4		
8. I have been helped by a volunteer(s) in the past and wanted to give something back.	0	1	2	3	4		
9. I have a unique expertise to contribute that the program needs.	0	1	2	3	4		
10. I wanted to fulfill a civic responsibility.	0	1	2	3	4		
11. I wanted to fulfill a religious obligation.	0	1	2	3	4		
12. I wanted to ease the pain of those in hospice programs.	0	1	2	3	4		
13. My religious and spiritual beliefs influence my ability to cope with issues of death and dying.	0	1	2	3	4		

Questions 14-45. How disturbed or made anxious are you by the following aspects of death and dying?  
 Read each item and answer it *quickly*. Don't spend too much time thinking about your response. We want your first impression of how you think right now. Circle the number that best represents your feeling.

	Very		Somewhat		Not
<b>Your Own Death</b>					
14. The total isolation of death.	5	4	3	2	1
15. The shortness of life.	5	4	3	2	1
16. Missing out on <i>so</i> much after you die.	5	4	3	2	1
17. Dying young.	5	4	3	2	1
18. How it will feel to be dead.	5	4	3	2	1
19. Never thinking or experiencing.	5	4	3	2	1
20. The possibility of pain and punishment during life-after-death.	5	4	3	2	1
21. The disintegration of your body after you die.	5	4	3	2	1
<b>Your Own Dying</b>					
22. The physical degeneration involved.	5	4	3	2	1
23. The pain involved in dying.	5	4	3	2	1
24. The intellectual degeneration of old age.	5	4	3	2	1
25. That your abilities will be limited as you lie dying.	5	4	3	2	1
26. The uncertainty as to how bravely you will face the process of dying.	5	4	3	2	1
27. Your lack of control over the process of dying.	5	4	3	2	1
28. The possibility of dying in a hospital away from friends and family.	5	4	3	2	1
29. The grief of others as you lie dying.	5	4	3	2	1
<b>The Death of Others</b>					
30. Losing someone close to you.	5	4	3	2	1
31. Having to see the person's dead body.	5	4	3	2	1

32. Never being able to communicate with the person again.	5	4	3	2	1
33. Regret over not being nicer to the person when he or she was alive.	5	4	3	2	1
34. Growing old alone without the person.	5	4	3	2	1
35. Feeling guilty that you are relieved that the person is dead.	5	4	3	2	1
36. Feeling lonely without the person.	5	4	3	2	1
37. Envious that the person is dead.	5	4	3	2	1

### The Dying of Others

38. Having to be with someone who is dying.	5	4	3	2	1
39. Having the person want to talk about death with you.	5	4	3	2	1
40. Watching the person suffer from pain.	5	4	3	2	1
41. To be the one to tell the person that he or she is dying.	5	4	3	2	1
42. Seeing the physical degeneration of the person's body.	5	4	3	2	1
43. Not knowing what to do about your grief at losing the person when you are with him or her.	5	4	3	2	1
44. Watching the deterioration of the person's mental abilities.	5	4	3	2	1
45. Being reminded that you are going to go through the experience also one day.	5	4	3	2	1

Questions 46-54. Please answer the following questions about yourself and your hospice volunteer work.

46. Age \_\_\_\_\_

47. Sex: \_\_\_\_\_ female \_\_\_\_\_ male

48. Racial or Ethnic group:

\_\_\_\_\_ Asian, Pacific Islander

\_\_\_\_\_ Black, non-Hispanic

\_\_\_\_\_ Hispanic

\_\_\_\_\_ Native American

\_\_\_\_\_ White, non-Hispanic

\_\_\_\_\_ Other

49. Number of years of education completed:
- |       |   |       |                     |
|-------|---|-------|---------------------|
| _____ | less than a high school education               | _____ | high school diploma |
| _____ | some college                                    | _____ | college degree      |
| _____ | master's degree                                 | _____ | doctoral degree     |
| _____ | other degree or education, please specify _____ |       |                     |
50. Number of years as a hospice volunteer, including this and any other hospice program. \_\_\_\_\_
51. In the last year, approximately how many families did you serve as a hospice volunteer? \_\_\_\_\_
52. **In** the last year, approximately how many hospice volunteer support meetings did **you** attend? \_\_\_\_\_
53. In the last year, approximately how many educational hospice workshops did you attend? \_\_\_\_\_
54. Which of the following best describes the type of community where you conduct your hospice volunteer work.
- |       |                          |       |            |
|-------|--------------------------|-------|------------|
| _____ | Remote / rural community | _____ | Small town |
| _____ | Small / medium size city | _____ | Suburb     |
| _____ | Large city               |       |            |

**If you have any additional comments that you think would be helpful, please write them below. Feel free to comment on any aspect of your hospice volunteer work and experience. Thank you for your time and your thoughts. I appreciate your contribution.**

## APPENDIX C

### Participating Maine Hospice Programs

Hospice of Eastern Maine  
PO Box 404  
Bangor, ME 04401  
(207) 973-8269

Hospice of St. Joseph  
St. Joseph Healthcare Park  
900 Broadway  
Bangor, ME 04401  
(207) 262-1810

Hospice Volunteers of Waldo County  
PO Box 772  
Belfast, ME 04915  
(207) 338-2268

Hospice of Midcoast Maine  
45 Baribeau Drive  
Brunswick, ME 04011  
(207) 729-3602

Downeast Hospice  
Calais Regional Hospital  
50 Franklin Street  
Calais, ME 04619  
(207) 454-7521

Hospice of Aroostook  
PO Box 668 Rt 89  
Caribou, ME 04736  
(207) 498-2578

Miles Home Health and Hospice  
RR 2 Box 4500  
Damariscotta, ME 04543  
(207) 563-4592

Pine Tree Hospice  
65 West Main Street  
Dover-Foxcroft, ME 04426  
(207) 564-8401

Hospice of Hancock County  
14 McKenzie Avenue  
Ellsworth, ME 04605  
(207) 667-2531

Hospice of Aroostook  
Northern Maine Medical Ctr  
Fort Kent, ME 04743  
(207) 834-3918

Hospice Volunteers of Kennebec Valley  
150 Dresden Avenue  
Gardiner, ME 04345  
(207) 626-1779

New Hope Hospice  
PO Box 757  
Holden, ME 04429  
(207) 843-7521

Hospice of Aroostook  
12 Kelleran Street #2  
Houlton, ME 04730  
(207) 532-9261

Hospice of Androscoggin  
PO Box 819  
Lewiston, ME 04243  
(207) 777-7740

Hospice of Maine, Inc.  
693 Rear Congress Street  
Portland, ME 04101  
(207) 774-4471

Hospice of Aroostook  
18 Dyer Street  
Presque Isle, ME 04976  
(207) 764-5762

Kno-Wal-Lin Coastal Family Hospice  
170 Pleasant Street  
Rockland, ME 04841  
(207) 594-9561

Hospice Volunteers of Somerset County  
PO **Box** 3069  
Skowhegan, ME 04976  
(207) 474-7224

Hospice of York  
1A Hospital Drive  
York, ME 03909  
(207) 363-7000

Hospice Program of Visiting  
Nurse Service  
15 Industrial Park  
Saco, ME 04072  
(207) 284-4566

Hospice Volunteers of the  
Waterville Area  
304 Main Street  
Waterville, ME 04901  
(207) 873-3615

## APPENDIX D

### Survey Comments

#### “Giving Back”

I became a hospice volunteer after watching a friend die in the hospital when she wanted to be home.

My main motivation to be a hospice volunteer was that my Mother died of cancer at the age of 51. I wanted to repay what I received from the hospice program in my community.

I knew I wanted to be a hospice volunteer after seeing my Mother-in-law suffer for a few years and die at the age of 67.

I was with my Mother at the moment of her death and have been forever changed. I knew then that I needed to become involved with hospice care.

I was alone with my husband when he died after a very short illness. I had some help from hospice, which is why I decided to “give back” to others by volunteering myself,

After experiencing the sudden death of a child I became aware of how important it is to be able to say goodbye.

Following my Dad’s death I decided I wanted to give something back.

After four very close relatives died and I had been taking care of them, I turned to hospice to learn about my own feelings and how I could best take care of someone else when I might have to.

The reason I volunteer, when my husband died twenty-three years ago there was no hospice available in our area.

I lost my Mom twenty years ago, I took care of her day in and day out, I watched her lose the battle with cancer inch by inch... when I learned of hospice a few years ago I vowed to give to others what I longed for so badly when my Mom died.

A family I was close to had a hospice team when their Father died, the wife and married children, the grandchildren were all very involved and couldn’t say enough good about the care they received from hospice. I

recently moved into a new community and decided to become a hospice volunteer myself.

My fourteen-year-old son committed suicide thirteen years ago. About five years ago I began speaking in public about this experience and discovered how helpful I could be for others. It was a natural progression from there into hospice work.

I became a hospice volunteer with main intentions of helping in my work, I am an elementary school secretary. Not only did I feel that being involved with hospice was an important way of dealing with my own family and friends deaths but also it would help with the emergency situations that would most definitely arise in the school environment.

Our teenage son was killed in an auto accident at the age of 16. After being served hospice bereavement support we wanted to give to other families what we had received – hope, courage, support and the feeling that we too could be survivors.

My motivation for becoming a hospice volunteer came from my own experience in the loss of someone dear.

#### Comments that Characterize the Religious and Spiritual Benefits of Hospice Volunteering

I became involved with hospice because of my work as a minister I work with dying people and their families offering spiritual support as part of my job, and I took the hospice training to help myself be better prepared for that work.

Hospice work seemed a good way to contribute to the well being of our neighbors as well as to be in service as ministry to others.

I am a servant of the Lord and want to serve not only Him but my fellow man.

I feel I was led into hospice volunteering by God, to learn coping and comforting skills.

I believe I was given the gift of helping families and their dying loved ones by God. I truly believe God gave this gift and cares for me as I respond to others in need.

I am motivated to hospice volunteer from a spiritual aspect – to share my gift of listening and compassion.

I do hospice work because I feel it's God's will for me, and also because I want to give of myself to my community.

Hospice led me to chaplaincy work at a local hospice and ordination in a local Church.

My belief in God and in afterlife influenced my ability to do hospice volunteering.

My spirituality is very eclectic and encompasses a reincarnation belief with Buddhist leanings in philosophy. Death to me is not an ending but merely a transitional phase, a mere stepping-stone and time for respite and reflection on a continual journey.

I have been blest by having four children so I do not have a choice but to give back to God and my community.

I have no fear of death, I believe death to be an enormously wonderful event. It is our chance to return to God.

People have told me that doing this kind of volunteer work is a gift. It has taken me quite a while to be able to say “yes”, this is a gift that God has given me. I'm thankful for this gift.

Hospice volunteering has strengthened my spiritual life.

It has been very enriching and inspiring to see people face death and dying with faith, grace and dignity, even when they struggle.

My faith is a strong basis for my work. I believe the moment of death and the time leading up to it to be a honor to share and a special part of living.

#### Comments on the Hospice Philosophy and Program

Hospice is a very rewarding program.. . I have benefited from it.

I strongly believe in hospice and what they can accomplish with those who are getting ready to meet their maker.

Hospice is really making a difference.

I believe very strongly in the philosophy of hospice.

This (hospice) is a special gift.

Hospice work is very important.

I love hospice work so much!

Words cannot express what hospice means to me!

Hospice is wonderful grace-filled work and program!

The hospice movement is wonderful and I'm very proud to be part of it.

Hospice is a great program.

Hospice is truly a remarkable program and much needed ministry, I am happy to be a small part of it.

I love the hospice philosophy and plan to become more involved with the program this year.

Hospice is a community and a family.

Hospice is a very good program.

I believe that hospice is a wonderful service to family, friends and to the person who is dying.

### Rewards of Hospice Volunteering

Hospice volunteering has helped me in making the transition to middle age, and that life still has tremendous value and meaning after your productive years of raising a family.

I volunteer because it makes me feel good to help people that are dying.

The training hospice volunteers receive is wonderful, emotional and spiritual experience.

Volunteering for hospice programs means so much to me – it's a priority. I always receive more than I feel I give.

I have and continue to benefit from my involvement in hospice care. The personal satisfaction of helping others. I've made a few lifetime friendships through my giving.

Hospice is a very rewarding program... I have enjoyed it.

It has truly been a blessing to help dying people. It is important work! An inner calm comes to me from being present in those hard times, I really feel supported by people I have known who have died.

I feel that it is a privilege to help nurture those who are dying.

The degree of fulfillment that arrives from helping others is what still comes as a bit of a surprise. I entered the hospice training thinking of how I could be of service to those in need of a little extra support in a time of need. When I receive from doing that it is immense. It is a gift!

Hospice volunteering gives me a purpose.

I enjoy helping others in need of hospice care and feel good about myself at the same time.

How special... to spend the last moments of someone's life with them!

Hospice volunteering has helped me to have the tools to listen compassionately without being uncomfortable with their pain and grief.

I always receive more than I give!

I get back so much more than I give. It is good for my soul.

I feel it is rewarding to be there to support the family.

I felt honored and humbled to be available to those in need.

Hospice work is the best thing I have ever done for myself. I hope I give as much back.

Hospice volunteering has been extremely rewarding.

Grand opportunity, and honor and privilege to be with others.

The rewards are tremendous. It is truly where I belong at this time of my life.

I like to make a difference in another person's life... to bring them comfort and peace.

The gift of those whom I have served far out-weigh what I bring to these special people. I feel very privileged to be involved in this aspect of their lives.

It never ceases to amaze me how the families accept me when I enter their lives. There is no better feeling or fulfillment than helping a hospice family through this hard time. I can't think of anything more rewarding... at least for me.

My life is fuller... more complete.

Hospice is definitely a most rewarding and gratifying program. I can truly say that I am "proud" to be a hospice volunteer.

Hospice involvement guides me daily in my thoughts and actions.

Hospice work is rewarding. It is a good feeling to be helpful to other lonely and/or painful human beings. Actually, in this work, you receive more than you give.

The most rewarding part of hospice for me is being able to support the caregiver.

I have received so much more from them than I have given and what I am able to give them is my time, time to listen and time to provide support and comfort.

Being a hospice volunteer has given me many rewards and respect for the dying person. They have taught me many things and have made me realize my feeling of death.

I find hospice work rewarding and even uplifting... especially when you know on that particular day that you helped that person better cope with their situation.

I have found my years as a hospice volunteer a very interesting, challenging, spiritual and broadening experience. Just great!

I am proud that I am doing something to help people along the path to dying.

I am proud and lucky to be a hospice volunteer.

Hospice volunteering is a wonderful experience.

If I ever felt full satisfaction in life, it has been my two years as an active hospice volunteer.

I have gained so much more than I have given. I feel privileged to be part of a families most personal and heart breaking time, knowing that I have somehow helped.

Volunteering with hospice has been one of the more rewarding experiences of my life.

Hospice work has helped me come to terms with the natural process of dying... perhaps at a sub-conscious level.

The most amazing thing about working with dying patients and their caregivers and loved ones is that no matter how much I may give in time and energy, loving and caring – I always get back so many blessings from these people, and learn so much.

I truly enjoy my volunteering and have found that I am a better person today because of my experience with hospice.

I find my volunteer work with hospice to be the most rewarding aspect of my life.

There are many benefits to hospice volunteering. The experience helps me gain perspective.

This experience has made me more sensitive and thoughtful when someone is sick or dying.

Hospice volunteering is very rewarding; your help is greatly appreciated, rewarding, and needed.

I feel that it is an honor and a privilege to have the opportunity to share time with someone's end-of-life care.

Being a hospice volunteer is a gift a family gives you that lets you into their homes, leaves you with their loved one for two hours and they trust you though they don't know you.

I learn and grow with each client, hospice in enriching my life and teaching me the skills, physically and emotionally, that I will need with my own family.

It has been very rewarding work. People who are dying are usually the only ones who truly know how to live. I have heaps of respect for that.

It makes me feel so good to see them brighten up when I make my visit.

It is very rewarding and has made a profound impact on the way I look at life and death.

I consider it to be a privilege to be allowed into these peoples lives at this special time.

There is no greater way to serve our brothers and sisters than as a hospice volunteer.

Being a hospice volunteer has changed my life forever. Their strength has been amazing to me. I hope to remain a hospice volunteer for many years.

The opportunity to spend time with the dying is precious.

I have learned to appreciate life and the resiliency of people.

Hospice volunteer work is extremely rewarding, The experience is teaching me much more than any classroom setting could. I will always be grateful to my families for so lovingly allowing me into their home and life. What they give to me almost seems more than what I give to them.

The experience that I have had in hospice work has been invaluable.

It is a warm feeling knowing that in some small way I made a difference for the individual and their family!

I really get so much out of this work, my philosophy is to listen, be present and be non-judgmental. It is appreciated.

Being a hospice volunteer has enhanced my life tremendously. It has been truly rewarding.

I have, and continue to benefit from my involvement in hospice care – from the personal satisfaction of helping others... I've also made a few lifetime friendships through my giving.

Hospice care of patients and families is a very rewarding continuation of forty-two years of pastoral care as an ordained clergy person.

### Comments on Death and Dying

I am not afraid of dying or what will become of me after death. I became involved in hospice volunteering because I was raised to believe (and continue to do so) that death is a very natural part (extension) of life and should be treated as such.

I admire those who have strong beliefs about “life after death”... I take strength from that and it quiets my fears.

I am most interested in the process of dying and being able to totally give love to someone who is dying in every step of the way, and not letting my/their fears get in the way of being able to “hold” the experience.

I love being involved in a project that gets people talking about death.

I am fascinated by the topic of death and dying.

At my age, death seems not so much terrifying but as a natural phenomenon that come to all of us.

My own death doesn't hold fear for me.

I look at death as a new beginning.

Being with those that are dying is a deeply moving experience.

The experience has been helpful and has really increased my interest in, and my awareness of issues of death and dying.

I have found the work very rewarding and helpful for me personally in dealing with death in my own family.

Hospice volunteering has helped me process through fear and loss, and make death “okay” now... only the anticipation of loss and loneliness remain.

The strength of their dying, their ability to share their dying, their humor and “humanness” are my rewards for volunteering.

Dying does not frighten me and I hope I’ve been a help to the families I worked with.

It never ceases to amaze me how well we prepare ourselves for the birth of a child but never seem to want to speak or prepare for our own death.

I don’t have a lot of anxiety about death, I **am** very comfortable being with someone who is dying.

I now know that the dying process can be anticipated, not feared, by both the client and his or her family members.

At this time of my life (age 71) dying doesn’t seem to be so scary.

My many clients have taught me not only about dying, but also about living.

I believe that in some cases death is the release from suffering.

My main personal motivation that got me involved in hospice was wanting to confront my own fears of dying. This is an ongoing process.

I feel that society shies away from talking about death and dying.

The deaths I have experienced in my own life have taught me more about living.

There have been too many life-ending episodes that I have witnessed and/or been part of with my clients and family to leave any doubts in my mind, heart and soul, that life is continual and that death is merely a period of rest, reflection, and reevaluation of the life that has just past and a preparation for the new life in which we will begin again, perhaps as a different sex, different race, and a different set of experiences in which to learn more of life’s lessons.

In all of my experience, I have witnessed the fact that no one enters death alone.

Assisting the dying comes natural to me. . . I pray for all of them. . . before and after they pass away. . . that is my contribution. . . and I feel comfortable with that.

I have always had a need to learn more about death and dying.

Hospice training and experience has helped me deal openly with my own personal “hang-ups” about death.

Dying is universal and those who are hospice volunteers have a common bond that ties them together worldwide.

I no longer worry about my death and dying, I accept whatever death he has planned out for me and will always find comfort through prayer that His will, will be my will.

My whole attitude about the “morbidity” of dying has altered. I came to see death as one more stage of dying, one for which most people are ready by the time they get there.

I’ve had years to contemplate death and become familiar with its inevitableness. I believe nature takes care of fear for most people.

I had a near death experience which has completely changed my feelings, fears, etc. of death.

I have been able to feel empathy and compassion for the family members, and joy for the person who has left their body.

My hospice training has made it easier for me to think about death and dying, and discuss it with my family.

I learn from each of my patients about life, death and dying.

A big part of my motivation in becoming a hospice volunteer was to learn more about dying and more about hospice as well as the usual altruistic motives.

The intimacy resulting from hospice work with the individual and their family is like nothing else.

As I am aging, I feel that life experiences have helped me to help others.

Hospice allows me to accept my own mortality.

There is a certain peace and release in dying that no one should fear, but actually welcome.

Death is very much a part of life and it is good to be able to help other face it in as comfortable manner as possible.

I believe even more strongly that death is part of the circle of life and we should celebrate that, even in our grief.

Death is not a huge problem for me.

I came to hospice in what I think of as a natural progression of my own life journey and spiritual development. The death of my own Mother has changed my view on death and dying... as well as the true meaning of life.

It is always a wonder and an honor to share another person's death, nearly all my clients have not chosen to talk about death, but rather life.

Death did not/does not scare me. It is simply something that happens.

The real reason I became a volunteer was to learn to better communicate with people and families in the death and dying situation.

I believe in life after death, and am comfortable with the process of dying.

The pioneer work we are doing has certainly lessened my fears about my own dying process and the options I have in end-of-life care.

I no longer "fear" death.

Hospice programs and working with the dying gives us the opportunity to experience the dying process in a society where people don't like to talk about death, or face it.

We are spiritual beings in human bodies, who we are never dies we just go back home. We are here to help each other through this process called life, be true to self... always.

You get to reflect on your own impermanence and help people with the most critical time of their lives.

I have worked with a couple of children and seen how their innocence enables them to face death and dying with simplicity.

It helped me to overcome my anxiety of being around death or the dying person. It helps me to understand the process of dying and how it will influence what I can do for my own parent, child or spouse.

There is definitely something special and almost mystical in being part of the dying process, even with someone who was a stranger such a short time ago.

Dealing with the death of another individual is very humbling.

I ~~am~~ quite peaceful about death.

In some ways I am preparing for what is inevitable, my own death. What I realize in preparing for my own death is that my priorities for what is truly important in this life become very clear, and that priority is to be of benefit to others.

I once was very afraid of death and dying primarily because I was sheltered from it as a child. When I was a young mother myself my father died of cancer, we only knew about his illness for three months before his death. Through his dying process I learned so much about death and loss... it was a gift to be present and involved.. . and it was then that I knew I wanted to become more involved and less sheltered from the realities of death. I now view the dying experience as a loss that can be witnessed and experienced as a gift to learn by.

## **BIOGRAPHY OF THE AUTHOR**

Anne Donovan was born the third of four children to Timothy and Rosemary Donovan. She moved with her family from California to Maine during her childhood and has remained in Maine since. After high school she worked as a bookkeeper and tax preparer for her father, a CPA. During her ten-year marriage she became a mother of two sons, Joseph and Timothy who continue to be her foundation in life. After her divorce she decided to enter college with the guidance of the Onward Program. Soon she discovered her passion for learning that led her through a successful undergraduate and graduate career at The University of Maine.

While pursuing her degree, she worked as a graduate assistant in Human Development and Family Studies for Dr. Marc. D. Baranowski. She is a member of the honor societies Phi Kappa Phi, The Golden Key Club, and Kappa Omicron Nu. She is also an active volunteer for Hospice of St. Joseph in Bangor, Maine. Anne is a candidate for the Master of Science degree in Human Development from The University of Maine in May, 2001.