Comparative Analysis of Hospice Bereavement Services in Alaska

Hospice….A special kind of caring

Prepared for:

Hospice of Anchorage
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Well has it been said that there is no grief like the grief which does not speak.
Henry Wadsworth Longfellow (1807 - 1882)

Table of Contents

<table>
<thead>
<tr>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preface and Acknowledgements</td>
<td>3</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>4</td>
</tr>
<tr>
<td>Introduction and Issue Statement</td>
<td>5</td>
</tr>
<tr>
<td>Client Information</td>
<td>7</td>
</tr>
<tr>
<td>Methodology</td>
<td>8</td>
</tr>
<tr>
<td>Literature Review</td>
<td></td>
</tr>
<tr>
<td>Government Regulations and Requirements</td>
<td>10</td>
</tr>
<tr>
<td>National Standards and Guidelines</td>
<td>13</td>
</tr>
<tr>
<td>Historical Hospice Surveys</td>
<td>26</td>
</tr>
<tr>
<td>Alaska Survey Results</td>
<td>32</td>
</tr>
<tr>
<td>Discussion and Recommendations</td>
<td>42</td>
</tr>
<tr>
<td>References</td>
<td>49</td>
</tr>
<tr>
<td>Appendix</td>
<td></td>
</tr>
<tr>
<td>Survey Participant Consent Form</td>
<td>56</td>
</tr>
<tr>
<td>Hospice Bereavement Services Survey</td>
<td>57</td>
</tr>
<tr>
<td>Survey Details</td>
<td>62</td>
</tr>
<tr>
<td>Hospices in Alaska</td>
<td>82</td>
</tr>
<tr>
<td>Hospice History and Development Timeline</td>
<td>83</td>
</tr>
<tr>
<td>Hospice Statistics and Demographics in the U.S.</td>
<td>90</td>
</tr>
<tr>
<td>Discussion of Grief, Bereavement, and Risk Factors</td>
<td>96</td>
</tr>
<tr>
<td>Barriers to Hospice Care</td>
<td>104</td>
</tr>
<tr>
<td>Bereavement Assessment Forms</td>
<td>105</td>
</tr>
<tr>
<td>Bereavement Flow</td>
<td>109</td>
</tr>
<tr>
<td>Job Description – Bereavement Coordinator</td>
<td>110</td>
</tr>
<tr>
<td>Volunteer Application</td>
<td>111</td>
</tr>
<tr>
<td>Hospice Resources</td>
<td>113</td>
</tr>
<tr>
<td>Evaluation of Hospice Care</td>
<td>118</td>
</tr>
</tbody>
</table>
Preface and Acknowledgements

This study was the culminating work in the University of Alaska Anchorage’s Master of Public Administration program, Public Management emphasis. I prepared this report in fulfillment of the program requirements, but also as a long term volunteer for the Hospice of Anchorage.

The circle of hands symbolizes the community of patients, families, doctors, health care professionals, Hospice Board Members, volunteers, and staff whose contributions of financial support, time, and skills ensure services for all in our community.

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Patti Homan, Section Leader for Hospice Bereavement Professionals, NHPCO, for identifying select articles and providing information.

A very special acknowledgement to Dennis Beckworth for providing encouragement and support during the several years I attended classes and especially during this capstone project.

We make a living by what we get, but we make a life by what we give.  

Winston Churchill
EXECUTIVE SUMMARY

Hospices generally provide two main components of care: care giving to the dying and bereavement care to those dying and to their family and friends. While bereavement care is an important value and a differentiated characteristic to hospices, it has received scattered attention and the allocation of minimal resources. (Lattanzi-Licht, 1989, p. ix) Hospice bereavement services have been called the “poor stepchild” within hospice programs. (Demmer, 2003) In addition, because there are limited federal and state requirements, hospice bereavement programs and services vary greatly between organizations and generally are loosely defined.

This project explores the form and function of the bereavement services component of hospice care, specifically bereavement programs in Alaska and looks at the following essential components of an effective bereavement program: assessment, bereavement services, budget and funding, data collection, and research.

A comparative analysis was conducted of the bereavement programs of Hospice of Anchorage and the other Alaska hospices with bereavement programs. These results were also compared with the results of two of the most comprehensive past national bereavement surveys (National Hospice and Palliative Care Organization/Marcia Lattanzi-Licht’s survey conducted in 1986 and reported in 1989 and Craig Demmer’s survey conducted and reported in 2002 with questions adapted from the Lattanzi-Licht survey).

The purpose of this study is to compare the Hospice of Anchorage bereavement program with those of national hospices and other Alaska Hospices with bereavement programs and provide some insight on how the Hospice of Anchorage program can better serve the public. Issues related to staffing, training, size, services provided, and service priorities are explored. Data collection, research, referrals, funding, risk assessment, and obstacles faced are examined.
INTRODUCTION AND ISSUE STATEMENT

We experience and grieve for many losses during our lives: death, traumatic experiences, divorce, relocation, job loss, loss of health and mobility. Death is probably the most pronounced cause of grief. For most people, the loss of a loved one to death is one of the most significant and stressful experiences of their lives.

I have been a long time caregiver and bereavement volunteer with several hospice programs, most recently with Hospice of Anchorage (HOA) in Anchorage, Alaska. Because of my interest in hospice, especially grief and bereavement, I have chosen an evaluation of hospice bereavement services provided by Hospice of Anchorage and other Alaska hospices as the focus for this project.

Death touches everyone. Each year millions of people experience the death of a family member from disease, accidents, natural disasters, violence, or natural causes. Steen (1998, p. 54) wrote that in any given year, 1 or 2 of every 10 American adults would lose a family member to death. One of every 20 U.S. children under the age of 15 would lose one or both parents to death. One-fourth of all pregnancies would end in miscarriage or abortion. In 1998, the number of widowed in the U.S. was over 15 million. In 2003, over 2.4 million people died in the U.S.; 1.8 million were over 65. By 2030, more than 3.5 million will die annually, over 2.6 million over 65. (Schumacher, 2003) Between 1993 and 2002, 26,879 Alaskans died, 10,183 of those lived in Anchorage. (Alaska Bureau of Vital Statistics, 2002) For more information, refer to the Hospice Statistics and Demographics section in the Appendix.

Hospice is considered the model for quality compassionate care for people facing a life-limiting illness or injury. Hospice focuses on caring, not curing. Hospice is not about death, but rather about the quality of life as it nears its end, for all concerned – the patient, family, friends, and the health professional community (DHHS, 2003a). “Hospice” is a philosophy, a paradigm of care, and an organizational form of health care delivery (Jennings, et al., 2003).

The word “hospice” originated in medieval times, a derivative of the Latin words “hospes” meaning host or guest and “hospitium” meaning guest house. (Odeen, 2000; HFA, 2003a) Hospice was originally a term for a place for travelers to rest while on a journey. Other sources say “hospice” came from the same linguistic root as words for hospital and hospitality and suggests notions of shelter, respite, and caring. (Neigh)

The concept of hospice care can be traced back to the 4th century AD when Fabiola, a Roman matron, opened her home to pilgrims, the sick, and the destitute as a Christian commitment. She chose the word "hospice" which referred to guests or strangers, their hosts, and the relationship of hospitality that developed among them. (CAPC Manual, 2002c)

The hospice concept was introduced to the U.S. when Dr. Cicely Saunders visited Yale University in 1963. Her lecture on the concept of holistic hospice care to medical students, nurses, social workers, and chaplains included photos of terminally ill cancer patients. (Odeen, 2000)

Healing a person does not always mean curing a disease. 
Dame Cecily Saunders

Give sorrow words; the grief that does not speak whispers the o’er-fraught heart and bids it break. 
William Shakespeare (1564–1616)
patients and their families that dramatically showed the differences between before and after symptom control. This contact set off a chain of events, which resulted in the development of hospice care in the U.S., as we know it today. (Neigh) Connecticut Hospice was established in 1974 in Branford, Connecticut in conjunction with Yale University. It is generally considered the first U.S. hospice to provide services in the home. For a more detailed discussion of the development of hospice, refer to the Hospice History and Development Timeline section in the Appendix.

Hospices generally provide two main components of care: care giving to the dying and bereavement care to those dying and to surviving family and loved ones. Hospice services are generally available to all regardless of race, religion, age, or illness. Bereavement support is considered an integral part of the comprehensive hospice approach. Hospice bereavement care supports those who mourn and provides education to assist in understanding loss and grief.

The Center for Advance Palliative Care Manual (2002b) defines bereavement as the state of having suffered the death of someone significant. Bereavement is a sense of loss felt when deprived of someone or something loved or valued. Bereavement is the way we process grief from the loss of a loved one through death; it encompasses grief and mourning and denotes the emotions and behavior of the person who has suffered a loss. (Egan and Arnold, 2003) Bereavement surrounding losses can be one of the most traumatic and stressful events in a person’s life. Grief is a normal and highly personal reaction to loss and bereavement support can play an important role in resolving grief, reducing the possibility of complicated grief reactions, and combating the negative health consequences of bereavement. (Demmer, 2003, p. 327-328)

While bereavement care is an important value and a differentiated characteristic to hospices, it has received scattered attention and the allocation of minimal resources. (Lattanzi-Licht, 1989, p. ix) Hospice bereavement services have been called the “poor stepchild” within hospice programs. (Demmer, 2003)

This project focuses on the bereavement services component of hospice care, specifically bereavement programs in Alaska and related assessment, budget and funding, data collection, and research surrounding bereavement. In this project, I explore the form and function of Hospice of Anchorage’s bereavement services. I adapted a survey created by the National Hospice and Palliative Care Organization (NHPCO, the largest nonprofit membership organization representing hospices and palliative care programs and professionals in the U.S.) and Marcia Lattanzi-Licht. This survey was administered to the hospices operating in Alaska with bereavement programs. I compared HOA with the other Alaska hospices and with the results of two of the most comprehensive national bereavement surveys conducted in the past (Lattanzi-Licht’s survey conducted in 1986 and reported in 1989 and Craig Demmer’s survey conducted and reported in 2002 with questions adapted from Lattanzi-Licht’s survey). The purpose of this study is to compare the HOA bereavement program with bereavement programs of national hospices and other Alaska Hospices and see if components of some of these programs could be implemented in the HOA bereavement program.

Because there are limited federal and state requirements, hospice bereavement programs and services vary greatly and generally are loosely defined. In 2002, NHPCO published “Guidelines for Bereavement Care in Hospice.” The purpose of the NHPCO Guidelines was to provide a framework for organizations to work within while allowing
Grief teaches the steadiest minds to waver.

Sophocles (496 BC - 406 BC)

CLIENT INFORMATION

Hospice of Anchorage (HOA) is located at 500 West International Airport Road, Suite C, Anchorage, Alaska. Julia Thorsness is the Executive Director and Lisa Fleischer is the Bereavement Coordinator.

HOA was founded in 1980 and provides support and care to people coping with terminal illness and grief in the Municipality of Anchorage. Hospice of Anchorage was organized by a group of committed founding members: Janice Livingston Olson, Dr. Mark Agnew, Father Norman Elliott, Jan Wills, Dr. Gerald Stranik, Lynn Chase, Fred Kehl, Fae Truskoski, Thelma Langdon, Leiea Knox, and David Veneziano. With some state funding, community educational workshops and outreach to local healthcare professionals was undertaken over the next 2 1/2 years.

In 1982, patient and family services were accomplished entirely by volunteers and volunteer nurses. In 1982, the first two part time office employees were hired; the first class of volunteers graduated, and the first membership drive was conducted. The first paid hospice nurse was hired in 1985.

Patients and families served grew from 20 in 1982/1983 to 122 in 1989. Currently, the average number of cases ranges from 100 to 120 a year.

Hospice of Anchorage provides services relating to the concerns of death and dying, terminal illness, end-of-life care, loss, and grief. HOA is a licensed provider of hospice care through the State of Alaska, a member of the NHPCO and a member agency of United Way. HOA is a non-Medicare certified hospice.

Hospice of Anchorage staff and volunteers assist in all areas of the program including providing direct patient care, education, fundraising efforts, and bereavement support.
When you are sorrowful look again in your heart and you shall see that in truth you are weeping for that which has been your delight.

Kahlil Gibran

METHODOLOGY

In 1986, Marcia Lattanzi-Licht, a consultant, educator, psychotherapist, and founder of the Boulder County, Colorado Hospice, collaborated with that hospice in surveying 439 U.S. members of the National Hospice Organization (NHO, renamed the National Hospice and Palliative Care Organization, NHPCO, in 2000) concerning bereavement services. There was a 61% return rate (N = 268) of the questionnaires. The Haworth Press published the results in 1989 in “Bereavement Care: A New Look at Hospice and Community Based Services.” This was one of the most detailed early surveys conducted on hospice bereavement services. The survey covered the form and function of NHO/NHPCO U.S. hospice bereavement programs. Issues related to staffing, training, size, services provided, and service priorities were explored. Data collection, research, referrals, funding, risk assessment, and obstacles faced were examined.

In 2002, Craig Demmer adapted the Lattanzi-Licht survey and mailed it to a random selection of 450 members of NHPCO members. There was a 58% return rate (N = 260). Demmer’s results, comparing the hospice bereavement services in the early 2000s with those in the late 1980s (the Lattanzi-Licht survey), were published in “Omega, Journal of Death and Dying” in 2003.

I obtained permission from The Haworth Press to use the original NHPCO/Lattanzi-Licht survey as a base. I adapted that survey by including additional questions developed with my client, Hospice of Anchorage Bereavement Coordinator, Lisa Fleischer. The additional questions were added to obtain more detailed information about the bereavement programs, budget information, and demographics of the clients served by each hospice, information that was not included in the original survey.

Virgene Hanna, Survey Director, University of Alaska Anchorage, Institute of Social & Economic Research (ISER) reviewed the adapted survey and made recommendations on organization and clarification of the questions. The Survey Participant Consent Form (which was received and signed by each bereavement coordinator completing the survey) and the Hospice Bereavement Services Survey are in the Appendix. Questions or answer options that were added to the original survey are indicated with an asterisk (*).

The data collection strategy was a survey where questions and forms were used to gather data from individual subjects. The adapted survey was administered to the Alaska hospices to collect data on the relevant variables as a snapshot of the bereavement programs currently existing in Alaska (a cross-sectional design). By comparing results from the Alaska surveys (2004) with the Lattanzi-Licht (1986) and Demmer (2002) surveys, long-term trends, if any, would appear (a time-series design).

The adapted survey used a combination of quantitative and qualitative research methods. Different measurement scales were used for different questions. Some were nominal; they identified and labeled categories without ranking them. Some were ordinal, ranking the possible answers. While some answers were numeric and could be
summarized, many answers produced word data that was difficult or impossible to convert to numbers.

Some survey questions were factual questions to elicit objective information from the respondents and some were opinion questions asking the respondents what they thought about an issue. Both open ended (where the respondent answered in their own words) and closed ended (where the respondent choose from a list of responses) questions were used. Some questions related to demographic information such as age, gender, and ethnicity.

The survey target population was the bereavement coordinator of all the hospices in Alaska with bereavement programs (N=9). Two Alaska communities have two hospices. My client, Hospice of Anchorage, and Denali Home Health and Hospice are in Anchorage. Hospice of the Central Peninsula and 1st Choice Home Health and Hospice are in Soldotna. Homer, Juneau, Sitka, Wasilla, Fairbanks, and Haines each have one hospice. All Alaska hospices have bereavement programs except Sitka’s Faith in Action. The response rate was 100%; however, not all respondents answered all questions.

<table>
<thead>
<tr>
<th>Participating Alaska Hospices</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice of Anchorage</td>
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<tr>
<td>Denali Home Health &amp; Hospice</td>
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<td>1st Choice Home Health &amp; Hospice</td>
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<td>Hospice of the Central Peninsula</td>
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<td>Hospice of Homer</td>
<td>Homer</td>
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<td>Hospice and Home Care of Juneau</td>
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<td>Valley Health Services - Hospice of Mat-Su</td>
<td>Wasilla</td>
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<td>Hospice of Tanana Valley</td>
<td>Fairbanks</td>
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<td>Hospice of Haines</td>
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In November 2004, I administered this survey in person to Lisa Fleischer in Anchorage. In December 2004, I contacted the other Alaska hospices bereavement coordinators by phone and explained this project and the survey. All agreed to participate. Because of the time constraints of the December holiday season and the work schedules of the bereavement coordinators, I e-mailed or faxed the survey to them. All surveys were returned to me via fax or e-mail during January 2005.

The survey results are presented in tabular format in the Survey Details section in the Appendix. One table presents results from the Lattanzi-Licht and Demmer surveys along with results from the Hospice of Anchorage survey and a combination of all the other Alaska hospices. An additional table presents the individual results for the other eight Alaska hospices completing the survey. I first entered the responses in an Excel spreadsheet but reverted to the table format, as it was visually more informative. Percentages were calculated manually. I evaluated survey results by looking at frequency distributions of the key variables related to bereavement services. No statistical or cross tabulation evaluation was attempted.
LITERATURE REVIEW

Government Regulations and Requirements

Even though Lattanzi-Licht (1989) described bereavement support as a vague catchall term that included many diverse activities and Demmer (2003) called hospice bereavement services the “poor stepchild” within hospice programs, there is some guidance about what constitutes hospice care and bereavement services. However, there are few detailed state or federal standards regarding bereavement programs.

The hospice movement in the U.S. developed so rapidly that the attendant rules, regulations, licensure, and accreditation systems associated with the health care industry was not initially able to keep pace. It was nine years (1974 to 1983) before there were requirements instituted under the hospice Medicare legislation, and longer for licensure and accreditation programs to become widespread. (Kilburn, 1997, p. 4)

The National Center for Health Statistics (2004), the Nation’s principal health statistics agency reporting to the U.S. Department of Health and Human Services (DHHS, 2003c), defines hospice care as a program of palliative and supportive care services providing physical, psychological, social, and spiritual care for dying persons, their families, and other loved ones. Hospice services are to be made available in both the home and inpatient settings. Home hospice care is provided on part-time, intermittent, regularly scheduled, or around-the-clock basis. Bereavement services are not specifically defined. Other types of counseling are to be made available to the family and other loved ones.

The Social Security Act defines a “hospice program” as a public agency or private organization primarily engaged in providing care and services, as needed, on a 24-hour basis, to a terminally ill individual. “Hospice care” means the following items and services are provided to the patient by a hospice program under a written plan established and periodically reviewed by the individual’s attending physician, by the hospice medical director, and by the interdisciplinary group of the hospice program:

- Nursing care provided by or under the supervision of a registered professional nurse
- Physical or occupational therapy or speech-language pathology services
- Medical social services under the direction of a physician
- Home health aide and homemaker services
- Medical supplies, including drugs and biologicals, and the use of medical appliances
- Physicians’ services
- Short-term inpatient care
- Counseling services (dietary, pastoral, and other) with respect to care of the terminally ill individual and adjustment to their death
- Any other item or service specified in the plan and for which payment may otherwise be made under the act

Sorrows are our best educators. A person can see further through a tear than a telescope.

Lord Byron
Counseling services must be available to both the patient and the family. Counseling includes bereavement care, provided after the patient’s death, as well as dietary, spiritual, and any other counseling services for the patient and family while the patient is enrolled in the hospice. Bereavement counseling is to be based on an assessment of the family/caregiver’s needs, the presence of any risk factors associated with the patient’s death, and the ability of the family/caregiver to cope with grief. There must be an organized program for the provision of bereavement services under the supervision of a qualified professional. The plan of care for bereavement counseling should reflect the family’s needs, a clear delineation of the services to be provided, and the frequency of the service. (Social Security Online 2; Centers for Medicare and Medicaid Services, 2004; DHHS, 2003d) There are no detailed guidelines addressing bereavement counseling, the organized program, or the bereavement plan of care.

The hospice interdisciplinary group providing care must include at least one physician (employed by or under contract to the hospice), one registered professional nurse, one social worker, and at least one pastoral or other counselor. The group must provide, or supervise the provision of, the care and services listed above, and establish the policies governing the provision of the care and services. (Social Security Online 2; Centers for Medicare and Medicaid Services, 2004)

Volunteers may be used to provide care and hospices must provide training that is consistent with the specific tasks the volunteers perform. Training should include:

- The volunteer’s duties and responsibilities
- The persons to whom they report or to contact if they need assistance
- Instructions regarding the performance of their duties and responsibilities
- Hospice goals, services, and philosophy
- Confidentiality and protection of the patient’s and family’s rights
- Family dynamics, coping mechanisms, and psychological issues related to terminal illness, death, and bereavement
- Procedures to be followed in an emergency, or following the death of the patient
- Guidance related specifically to their individual responsibilities

(Centers for Medicare and Medicaid Services, 2004)

Medicare is the medical assistance provided in Title XVIII of the Social Security Act. Medicare is a federally funded health insurance program administered by the Centers for Medicare and Medicaid Services for persons 65 years and older who have worked 40 Social Security quarters and for disabled persons who are eligible for benefits. It covers approximately 39 million people. Eligibility is not based on income.

Medicare provides coverage for a variety of services and products designed for those with a terminal diagnosis. A physician must certify that the patient (beneficiary) has a terminal diagnosis with a six-month prognosis of death, if the illness runs its usual course. Hospice care that is covered by Medicare is chosen for specified amounts of time known as “election periods.” A physician may certify a patient for hospice care coverage for two initial 90-day election periods, followed by an unlimited number of 60-day election periods. Each election period requires that the physician certify a terminal illness. Since terminal illnesses do not have entirely predictable courses, the benefit is available for extended periods beyond six months. (DHHS, 2003a) The six-month
A prognosis requirement is cited as one reason many hospices elect to not be Medicare-certified. That requirement prevents them from working with many patients. Refer to the Barriers to Hospice Care section in the Appendix for a discussion of other obstacles to hospice care.

Hospice care has been a fully covered Medicare Part A benefits option since 1983. Covered services include: medical and nursing care, medical equipment (such as wheelchairs or walkers), pharmaceutical therapy for pain relief and symptom control, home health aide and homemaker services, social work services, physical and occupational therapy, speech therapy, diet counseling, case management, and bereavement. (DHHS, 2003a)

Medicare-certified programs must provide bereavement counseling for the patient before their death and bereavement services for family members for at least one year after the death, however, components of an acceptable program are left to the discretion of each hospice. (Foliart, et al., 2001; Moon and Boccuti, 2002; Demmer, 2003) There are no other detailed guidelines about bereavement care.

Certification refers to agency certification by Medicare and/or Medicaid. Both programs can certify hospices as meeting agency conditions for participation (CoP). Conditions for participation address issues of professional management, the plan and continuation of care, informed consent, in-service training of staff, licensure, short-term inpatient care, and staffing of qualified personnel. (National Center for Health Statistics)

Medicaid is the medical assistance provided in Title XIX of the Social Security Act. Since 1965, Medicaid has been a jointly funded Federal and State health insurance program that covers approximately 36 million people. Medicaid is a means-tested (the prospective recipient’s income and savings are examined to see if they meet the criteria for this assistance) entitlement program for low-income people. Medicaid covers hospice care, including bereavement and other counseling services, in many states. Here, too, there are no detailed descriptions of what constitutes bereavement care.

Alaska joined the Medicaid Program in 1972 and the Alaska Legislature selected hospice services as an optional covered service. In Alaska, Medicaid is administered by the Department of Health and Social Services. Medicaid does not directly reimburse for bereavement services. (Welcome to Medicaid, 2001)

Hospice care is a covered benefit under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations; however, services, especially bereavement services, are not necessarily reimbursed to the provider. (E-mail, Thorsness, 2004)

The Social Security Law, SEC. 1814 [42 U.S.C. 1395f], states that no payment may be made for bereavement counseling and no reimbursement may be made for other counseling services as separate services. (Social Security Online 1) Medicare does not cover bereavement and pastoral care services outside of the hospice program. (Moon and Boccuti, 2002, p. 1, 7) Bereavement services are included in the overall hospice benefit but are not billed separately by hospices. (E-mail, Thorsness, 2004). The DHHS states, “bereavement counseling is a required hospice service, but it is not separately reimbursable.” (Kilburn, 1997, p. 341; DHHS, 2003b)

Legislators felt bereavement support was the responsibility of one’s personal clergy, not of a hospice, and excluded this service from the 1982 Hospice Medicare
legislation. In addition, at that time, there was little documentation of hospice bereavement services or of their effectiveness. (Lattanzi-Licht, 1989, p. 2)

Alaska Statute 18.18.100, Requirements For Licensure (for hospice programs), states bereavement services (must be provided) for at least one year after the death of the person who is terminally ill. Further, a hospice program shall provide an educational program that offers a comprehensive overview of hospice philosophy and hospice care and the program must include the following: hospice philosophy; family dynamics; pain and symptom management; spirituality; communication skills; volunteer roles; multidisciplinary management; psychological perspectives on death and dying; and grief, loss, and transition. (ALRC, 2004) Here, too, there are no other detailed descriptions of what constitutes bereavement care or a hospice bereavement program.

**National Standards and Guidelines**

Founded in 1978, the National Hospice Organization (NHO) is the oldest and largest nonprofit membership organization representing hospice and palliative care programs and professionals in the U.S. Members include hospices, palliative care programs, grief and bereavement centers, education and research organizations, foundations, home health agencies, companion services, medical supply companies, pharmaceutical organizations, staffing agencies, software vendors, and health care consultants. In 1993, the NHO defined bereavement practices and outcomes among hospices in the U.S. The following seven elements were included.

- A written plan for bereavement intervention, initiated at admission, is to be developed before providing bereavement care.
- The plan should be based on an assessment of the needs of the bereaved family; should recognize their social, religious, and cultural values; and include an assessment of potential pathological grief. The plan is to extend to at least 1 year after the death of the patient and can include individual counseling, support groups, letters, and cards.
- At a minimum, the bereavement plan needs to document an assessment of risk factors; goals; the scope, type, and frequency of follow-up services; and the family’s acceptance of bereavement services.
- Counseling services should provide information and support during all facets of the dying and grieving process to help the patient and family cope with terminal illness, death, and bereavement.
- Hospice bereavement services must provide qualified staff and volunteers. Volunteers should receive appropriate documented orientation and training in bereavement practices.
- Survivors with potential pathological grief reactions are entitled to receive referrals for appropriate counseling services including referrals for family members outside the geographic area for bereavement follow-up.

*Hope is grief’s best music.*

*Proverb*
• Documentation in the hospice services record should be descriptive, accurate, and include potential bereavement complications and care provided from admission through the bereavement process.

In 2000 the NHO was renamed the National Hospice and Palliative Care Organization (NHPCO). NHPCO currently represents over 80% of the hospices nationwide and over 90% of the patients served in 2002 received hospice care by NHPCO members. (NHPCO, 2004) In 2002, NHPCO published “Guidelines for Bereavement Care in Hospice.” Over 80 members of the Bereavement Professionals Section of the National Council of Hospice and Palliative Professionals of NHPCO worked together to create the guidelines. The focus of the guidelines is on the care of families following a death. The purpose was to provide a framework for organizations to work within while allowing room for the wide variety of bereavement programs in existence. The guidelines provide information and identify resources so that local hospice professionals can put regulations and standards into practice and further develop their hospice and community bereavement programs. The guidelines do not replace any local, state, or federal regulations or standards. They cover essential components of an effective hospice bereavement program and, when followed, promote the provision of professional, effective bereavement services and advance the practice of quality hospice and community bereavement care. (NHPCO, 2002, Introduction; E-mail, Homan, November 2004)

In the following discussion, I cover the main components of a hospice bereavement program: assessment, services provided, budget and funding, data collection, and research. Some background information is provided for the NHPCO guidelines, regulatory requirements (if any) are indicated, and then the guidelines and standards are discussed for these aspects. All background, regulatory requirements, guidelines, and standards come from the NHPCO publication issued in 2002.

Assessment

Medicare COP: 418.88(a) states there must be an organized program for the provision of bereavement services under the supervision of a qualified professional. The plan of care for these services should reflect family need, as well as a clear delineation of services to be provided and the frequency of service delivery (up to one year following the death of the patient). (NHPCO Guidelines, 2002b, p. 9)

The first vulnerability questionnaires and risk assessment forms arose out of concerns about the high incidence of suicide in some of the bereaved families who were cared for by hospice. (Renzenbrink, 2002, p. 9)

The assessment provides the groundwork for determining which bereavement care services should be provided. The assessment should address family and significant others’ grief/bereavement responses and needs on physical, emotional, social, spiritual, and other related levels. Assessment of these responses and needs begins at the time of the hospice patient’s admission to the hospice program and continues throughout the period of patient care, death, and bereavement care provided by the hospice. (NHPCO Guidelines, 2002b, p. 8)

Adequate assessment is necessary within the hospice setting so that individuals are offered or can be referred to the appropriate level of service. (Walsh-Burke, 2000, p.
82) Assessment of the needs of family and friends in bereavement care should begin before the patient’s death, ideally, from the time of diagnosis and throughout the illness (Egan and Arnold, 2003, p. 46). An essential part of bereavement assessment is determining whether the problems identified are representative of a normal grief response or are more pathological. (Kilburn, 1997, p. 211) For more information, refer to the Discussion of Grief, Bereavement, and Risk Factors section in the Appendix.

The Hospice Operations Manual (Kilburn, 1997) outlines the following format for bereavement assessment:

- Name, address, phone number, age, and marital status of bereaved
- Relationship to deceased
- Length of involvement with hospice
- Was this person the primary caregiver
- Physical responses to grief: sleep disturbances, eating disturbances, cigarette abuse, substance abuse, drugs, alcohol, changes in appearance, medical problems, etc.
- Emotional responses to grief: story of terminal illness told, expressions of loss/sadness, anger, guilt, denial, suicidal ideation, living in present/has resumed former activities, planning for future, etc.
- Life and family support or stresses: family availability, other family stresses, friends in area, church/community involvement, other social activities, receiving other supportive services e.g., support group, psychotherapy, etc.
- Adequacy of finances: problems with financial management, processing third-party insurance claims, employment, etc.
- Risk factors that may indicate the need for more intense intervention are:
  - Suicidal ideation
  - Substance abuse at a level where the person has difficulty with day to day functioning or that is health threatening
  - Severe depression, where the person is unable to perform the majority of activities of daily living
  - Loss of control that might result in a danger to self or others
  - Any problem in which the assigned volunteer or staff person feels “over their head” in terms of skills to assist the grieving person

One of the goals and standards of hospice bereavement care involves the assessment of high risk factors among bereaved hospice clients. NHPCO guidelines (2002b, p. 8) state at the time of the patient/family’s admission to the hospice program, the interdisciplinary team should assess the grief and loss needs of all concerned. Grief and loss needs of the patient are addressed during the provision of patient/family hospice services. In addition, the interdisciplinary team should complete a survivor risk assessment that evaluates pertinent family member’s risk for developing complications in bereavement as well as identify strengths, vulnerabilities, grief and loss needs, and related concerns of family members.

Following the patient’s death, a bereavement assessment should be completed. This assessment should also address survivors’ strengths and vulnerabilities, grief and loss concerns, and related needs of identified family members after death. The assessment should consider the length of the patient’s illness and the family’s preparation for death, as well as their risk for developing complications in bereavement. The
bereavement assessment should be completed between four and eight weeks following the death by a qualified bereavement professional so that sufficient time has passed since the death to gather important assessment information (NHPCO Guidelines, 2002b, p. 8). Intervention, support, and care provided to the family following the patient’s death should be based upon the concerns and needs identified in the assessment and documented in a bereavement plan of care.

The assessment should not be a singular event, but rather an ongoing process throughout the time bereavement care is provided. The ability to assess family members’ coping on an ongoing basis is dependent upon their active participation in bereavement services. (NHPCO Guidelines, 2002b, p. 8)

The survivor risk assessment should be available to all team members including bereavement personnel. The bereavement assessment should be available to team members who, for some identifiable reason, have a need to know the contents of the assessment. Both should be documented in the medical record in a clear and understandable form. (NHPCO Guidelines, 2002b, p. 8)

NHPCO guidelines (2002b, p. 8-9) state the assessment should address the following areas as related to the family and significant other milieu (surroundings or environment):

- **Physical:**
  - Current health status and impact of grief
  - Medical concerns for/of identified family members/significant others and their impact upon care giving
  - Ability to take care of self and perform activities of daily living
  - Impairment as a result of substance abuse
  - Change in sleeping or eating habits or patterns, stamina, and energy levels

- **Emotional:**
  - Ability to engage in emotional expression
  - Feelings of loss, sadness, hopelessness, conflict, frustration, anger, irritability, guilt, self-reproach, fear
  - Suicidal ideation and risk
  - History of mental health and/or psychiatric problems/intervention
  - History of loss or grief

- **Social:**
  - Family interaction and function
  - Relationship with patient
  - Degree of satisfaction with life closure tasks of patient/family prior to death
  - Support system
  - Social outlets, work, career and/or meaningful activities
  - Culture or ethnicity factors

- **Spiritual:**
  - Degree of spiritual distress
  - Outlook (attitude), direction, and purpose in life
  - Meaning and value in life
  - Sense of “community”
• Role of faith and spirituality
• Ability to access hope for the future
• Economic:
  • Financial stability, employment status, dependents, and debt burden
• Intrapersonal:
  • Self-esteem, self-worth, self-confidence, and self-perceptions of competence
  • Independence vs. dependence
  • Ability to adapt to new roles or responsibilities
  • Personal strengths and weaknesses
  • Coping resources and strategies

Bereavement Services

Medicare COP: 418.88(a) states there must be an organized program for the provision of bereavement services (NHPCO Guidelines, 2002b, p. 10) but does not define bereavement services.

People deal with grief in different ways and may or may not need bereavement support, or may need different amounts or kinds of support. Just as there are different types of grief and different ways of reacting to grief, there are different bereavement services offered by hospices. The assessment determines which bereavement services to offer. To address the needs of people experiencing grief and bereavement, hospice provides continuing contact and support for family and friends for at least a year, and in most cases for 13 months following the death. Because of the uniqueness of the individual perception of loss and the expression of grief, it is imperative that hospice bereavement programs provide a variety of services to promote effective grieving.

The National Hospice Organization Operations Manual (Kilburn, 1997) defines bereavement services as those services to the patient, family, significant others, or other primary caregiver from the point of admission to a hospice through the bereavement period following the death of the patient. Bereavement services focus on helping the patient and significant others cope with death related grief and loss. Any member of the hospice interdisciplinary team may provide these services, though they are most commonly provided by a social worker, pastoral or other counselor, nurse, or volunteer who has received appropriate training.

Identifying the availability and scope of hospice bereavement services to be provided to hospice families and the community at large provides clarity, focus, and definition for the bereavement program. Defining the scope of services to be provided ensures that hospice patients and families know what to expect, that the overall organization and specific bereavement staff understand their roles and responsibilities, and helps ensure bereavement professionals have the requisite knowledge and skills needed to provide these services. (NHPCO Guidelines, 2002b, p. 10)

Based upon current knowledge and understanding of the grief process and accepted standards of practice, hospice bereavement care should focus on:
• Helping family members understand and move forward in the grief process by
  • Facilitating their expression of thoughts and feelings
  • Helping them identify or develop and utilize healthy personal coping strategies
• Helping with problem-solving around adjustment issues
• Providing guidance about decision-making
• Addressing social and spiritual concerns
• Assisting survivors to adapt to an environment without the deceased while experiencing a continued (transformed) relationship with the deceased (NHPCO Guidelines, 2002b, p. 10)

*Individual Services* - Hospices in the U.S. have developed a continuum of bereavement services to meet the various needs of individual clients. The level of service should be matched with the intensity level of grief (identified in the assessment) as shown in the following table developed by Walsh-Burke (2000, p. 79).

<table>
<thead>
<tr>
<th>Level of Grief Intensity</th>
<th>Least</th>
<th>Less</th>
<th>More</th>
<th>Most Intensive</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Continuum of Bereavement Services</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow up calls</td>
<td>Support/psycho-educational groups</td>
<td>Bereavement counseling</td>
<td>Grief therapy or psychotherapy</td>
<td></td>
</tr>
</tbody>
</table>

Bereavement support can play an important role in resolving grief, reducing the possibility of complicated grief reactions, and combating the negative health consequences of bereavement. (Demmer, 2003, p. 327-328) Bereavement support or intervention may include empathic affirming of reality, normalizing, providing grief education, supporting the grief process, and identifying and referring high-risk grievers for professional therapy. (Steen, 1998, p. 64) Genevro (2003, p. 59) found that hospices provide bereavement care on a regular basis that incorporates a variety of elements, including pastoral care, written information, and contacts by telephone or in person.

Egan and Arnold (2003) outlined some standard approaches of bereavement support. Normalizing grief involves telling the bereaved that their grief is normal and that there is no “right” way to grieve. No two people, even with similar experiences, grieve in exactly the same way. It is important not to compare someone’s experience with your own loss or to other’s losses. Offering comfort is normal. Simple gestures such as attentive listening, eye contact, stillness, gentle touch, or silence may be effective. Efforts to remove emotional pain can hinder the grieving process; pain is a necessary component of grief (Egan and Arnold, 2003, p. 50). Encouraging the bereaved to identify and express their feelings can alleviate stress and allow problem solving. Talking about their loved one helps the bereaved begin to accept the loss emotionally and plan for and respond to changes in their lives. Many hospice groups start with each member briefly “telling their story.” Rituals and traditions such as funerals, memorial services, burning a candle, planting a tree or bush, or making a picture board or photo album of the deceased can serve to acknowledge the death. These activities may be repeated on the anniversary of the death.

Grief education is another standard approach of bereavement support. Literature on grief, lending libraries, group meetings, and individual grief counseling where people share feelings, experiences, and solutions may be helpful. Some knowledge of “what to expect” helps many.
Because of the uniqueness of the individual perception of loss and the expression of grief, hospice bereavement programs should provide a variety of services to promote effective grieving. NHPCO Guidelines (2002b, p. 10) state hospice bereavement programs should provide, at a minimum, the following services:

- Assessment of survivor’s coping with death and identification of the risk potential for complicated grief
- Education about grief and bereavement, applicable to children as well as adults, through written materials, groups, classes, counseling, and related services
- Opportunities for support and facilitation of thoughts and feelings surrounding loss through groups, classes, counseling, personal contact, special events and/or related services, for children as well as adults
- Appropriate referral to agencies and practitioners when the needs of the bereaved are beyond the scope of the hospice bereavement program
- Appropriate referral to grief support groups and other appropriate resources available in the bereaved’s community
- Clear and appropriate information about the length of bereavement services and effective closure with the family when services are completed

Hospice bereavement programs may offer any of the following:

- Home or office visits, mailings, e-mail contact, and phone calls
- Support groups
- Hospice open houses, pot luck suppers, memorial services, annual remembrance services, or other planned events
- Written materials or videos about the grieving process and common reactions to it
- Attendance at funeral rites by key members of the interdisciplinary team involved in the care of the patient and family (Kilburn, 1997, p. 140 - 141, 209 - 210)
- Spiritual care, psychological, grief, or other counseling for the patient, family, significant others, or care givers
- Educational seminars

Support Groups - Support groups, in one form or another, are one of the most frequent bereavement services provided by a hospice.

Bell and Bevis (1989) discussed the therapeutic nature of bereavement support groups. The principle behind the support group concept is that people who have experienced a certain condition can truly empathize and understand what another individual is going through when they are in that condition, more so than someone who has not experienced that condition. There is a sense of empathy and shared experience that provides relief to group participants.

Bereavement groups have certain qualities. Participants are trying to cope with a condition that feels to some as an illness and to others as craziness. Group participants
are full of overwhelming and frequently unmanageable feelings. They are searching for affirmation, validation, and sometimes education about the grief process. They want to know about what they are going through and how to survive it. Group members have common feelings, experiences, and thoughts. As these are shared, members experience a reassurance that they are all right, normal, and not going crazy. The bereaved person has come into a social situation from comparative isolation. That action is significant. The bereaved person can talk about, be angry at, and cry for the person who has died. The grief group gives confirmation and permission to act out this healing process. This is one of the most significant benefits a group offers. (Buell and Bevis, 1989)

The group facilitator and group members actually affirm the bereaved's need to feel the way they do for the time being. The bereaved receives permission and encouragement to explore and describe the feelings they have. Healing can require a witness to the pain and grief (Buell and Bevis, 1989, p. 109). The ability of the group to allow time for grieving is another of its major benefits.

Generally, bereavement groups should have a facilitator. Buell and Bevis (1989, p. 111) gave several reasons for this. First, many groups run by participants dissolve when the needs of the main participants have been met. Second, the intricacies of interaction require a skilled person to avoid monopolization, to be alert to complications that might require referral to professional help, to bring clear information to the group, and to provide continuity. If more than one facilitator is paired with a group, each has a back up, mutual supervision, and they can share the burden of providing continuity at every meeting.

The main criterion for participation in a group should be having experienced a loss through death. The time since the death is not particularly important, unless the bereaved is still in a state of shock or close to the time of the death. Then they may not be able to actively participate and share with the group effectively. (Buell and Bevis, 1989) Their grief may be too fresh.

There should generally be a screening process before a person can enter a group. Buell and Bevis (1989) outline several criteria for bereavement group membership:

- An expressed desire to be with others in a group experience
- No evidence of a psychotic disorder
- No evidence of drug or alcohol addiction
- Some ability to express relevant thoughts and feelings about the death

Individuals do not have to be highly verbal, but for the group to be effective, some sharing is required by all group members. Participants are generally asked to attend a certain number of sequential sessions. The first session may be extremely painful for a new group member but to be effective they need to attend more than one meeting. In addition, it takes several meetings for the bonds and a sense of community to develop between group members. (Buell and Bevis, 1989, p. 113)

Buell and Bevis (1989) conclude that hospice programs could reintegrate their hospice families into the larger community by merging hospice survivors with those who have had losses of similar kinds. Bereavement groups are opportunities to teach, to serve the community, and to enrich the group members.

Counseling - In 1983, C. Murray Parkes reported that bereavement counseling reduced the risk of psychiatric and psychosomatic effects of bereavement and assisted in the healthy resolution of grief. Jacobs (1987) reported bereaved persons had higher
You don’t heal from the loss of a loved one because time passes, you heal because of what you do with the time.  

Carol Crandall

scores on anxiety and depression than the nonbereaved; however, these symptoms diminished over time. The philosophy of bereavement is that bereavement support for survivors can assist in the prevention of adverse reactions to the death. (Longman, 1993)

Hospices generally offer one-on-one bereavement counseling with a social worker or trained volunteer.

Referrals - Hospice clients should receive information about and referral to other community resources if needed. A list of community resources should be available and should include all appropriate and applicable community support groups, programs, and agencies designed specifically to address issues of grief and bereavement. The bereavement program should also have a list of qualified community mental health agencies, psychiatric treatment facilities, agency and individual practitioners available to assist in situations of complicated grief, mental health, psychiatric illness, or other areas beyond the scope of the hospice bereavement program. Hospice should also provide information to facilitate access to bereavement services for family members who live outside the hospice’s service area. (NHPCO Guidelines, 2002b, p. 25)

Community Services – Hospice is a key resource for bereavement education and services in the community. Bereavement services should be available to all community members as well as hospice families. Hospice bereavement services should cover gaps in what the community provides and should avoid duplication of bereavement services and/or efforts being provided by others that are appropriate and effective in meeting community need. (NHPCO Guidelines, 2002b, p. 14)

Even though the hospice bereavement program may not have the resources to provide the services itself, hospice can work with other community leaders to help develop programs to address unmet needs. (NHPCO Guidelines, 2002b, p. 7, 10, 21)

Rather than compete with community agencies, programs, and services providing similar and related grief and bereavement services (including hospice programs), hospice bereavement professionals are encouraged to enhance, improve, and expand resources for the bereaved. Collaborative efforts between hospice and other service providers are strongly encouraged to actually increase the resources available to meet community’s bereavement needs. Bereavement professionals should strive to develop good and effective working relationships with existing community resources and should work to identify and collaborate with other community professionals who can be an appropriate referral resource for individuals and families beyond the scope of the hospice bereavement program. Opportunities to learn about the specific bereavement needs and practices of divergent populations that are available through such collaboration will enhance the understanding and effectiveness of bereavement professionals and promote their awareness of and attention to the diverse bereavement needs of their communities. (NHPCO Guidelines, 2002b, p. 14)

Hospice bereavement programs are encouraged to accept referrals for hospice bereavement care from hospices outside their service areas and to provide a full range and scope of bereavement services to family members whose loved one received hospice care in another location. (NHPCO Guidelines, 2002b, p. 14)
NHPCO Bereavement Guidelines (2002b, p. 12-13) outline the following for community bereavement services. Such services may include, but are not limited to, the following:

- Grief educational seminars
- Professional educational seminars
- Written information about grief and coping
- Library for community circulation
- Bereavement counseling
- Support groups or referral to support groups such as: Mothers Against Drunk Driving – MADD; Compassionate Friends; Survivors of Suicide – SOS; National Organization of Victims Assistance – NOVA, etc.
- School-based grief groups
- Consultation services
- Critical Incident Stress Management
- Trauma and disaster response
- Socialization activities/groups
- Referral to community practitioners and agencies

Community bereavement services may be targeted, but are not limited to, the following populations:

- Widowed persons
- Bereaved children and families
- Adults grieving parental loss
- Bereaved parents, including perinatal loss
- Bereaved homicide and suicide survivors
- Disenfranchised mourners (i.e. those whose grief is not socially sanctioned or supported)
- Trauma/disaster survivors
- Funeral home clients
- Medical facilities (residents and staff), long term care facilities (residents and staff), mental health agencies, emergency medical staff
- Faith Communities (clergy, bereavement ministry staff, volunteers, etc.)
- Schools (teachers, counselors, students)
- Workplace (employee assistance programs, corporations, employees)
- Child Protective Services, Foster Care, Out of Home Placement
- Prison ministries, juvenile facilities
- Law enforcement agencies
- Professional practice organizations

*Ethnic and Culture Issues* - Attention to and respect for the ethnicity and cultural background of hospice clients is essential in the development and provision of appropriate bereavement services. Hospice staff should learn and understand the beliefs, values, perspectives, and practices of diverse populations in the community with respect to death and dying, grief and bereavement. In addition, bereavement services should be offered to people regardless of their age, race, sex, socio-economic status, educational level, or chosen lifestyle. All persons should have bereavement support readily available. Hospice bereavement professionals should also identify and collaborate with community
agencies devoted to addressing the needs of minority populations in its service area. (NHPCO Guidelines, 2002b, p. 19)

**Budget and Funding**

There are no regulatory requirements or recommendations regarding budgets or funding. The DHHS states, “bereavement counseling is a required hospice service, but it is not separately reimbursable.” (Kilburn, 1997, p. 341; DHHS, 2003b)

The value of services to an organization is often related to the budget dollars allocated to those services. To provide quality bereavement services (to both hospice families and the community at large), hospices should have adequate financial resources, especially since there is no avenue for collecting from Medicare, Medicaid, HMOs, private insurance plans, or other managed care organizations.

Ideally, there should be a budget with funds earmarked for the bereavement program. One of two budget formats could apply. A performance budget format emphasizes agency-activity performance objectives and accomplishments. This budget format focuses on activities, output, management, and efficiency. A program budget format organizes proposed expenditures according to output or contribution to the hospices objectives. This budget format focuses on achievements, outcomes, planning, and effectiveness. (Mikesell, 2003, p. 186-195)

Bereavement programs are considered preventive models of care (programs that facilitate healthy grieving and prevent the development of grief-related illnesses and health care problems) rather than treatment oriented programs. Therefore, bereavement services are not covered by the reimbursement mechanisms available for other medical or mental health services (health care insurance companies, state agencies, Medicare, or Medicaid)

Although bereavement counseling is provided to hospice family members as part of a comprehensive program of services without charge, some hospices request payment or make a request for “suggested donations” for special programs and groups. Such fees should not create an access barrier to hospice family members with regard to bereavement services. Hospice bereavement programs that choose to charge fees for services should establish clear and consistent fee guidelines as well as make provisions for scholarships or other supplements to ensure access to services without regard to ability to pay. (NHPCO Guidelines, 2002b, p. 21)

Some hospice programs identify “core” bereavement services that are provided to hospice bereaved families at no cost. Other programs and services outside the “core” program have a fee attached for hospice family members. Examples of services that may fall outside core offerings are children’s camps, adult retreats, and some specialized support groups. (NHPCO Guidelines, 2002b, p. 21)

As hospice programs become recognized for their quality of bereavement services, requests from the community for bereavement services to non-hospice bereaved people are made. The Standards of Practice for Hospice Programs (NHPCO Guidelines, 2002b, p. 21) states hospice programs should provide these services. Hospice bereavement programs must identify their community’s needs for grief and loss services, determine how to meet those needs and determine what, if any, fees will be charged. Clear and consistent fee guidelines should be developed and decisions should be made regarding reduced fees or scholarships for those without adequate means. (NHPCO Guidelines, 2002b, p. 21)
Because adequate funding for hospice bereavement services is a significant challenge, hospice programs often seek additional funding beyond that allocated to the bereavement program by the hospice or obtained by fees. The hospice may use development or fund raising resources to develop projects and seek outside funding for bereavement care. Public or university libraries and the Internet are resources to locate listings of foundations and their guidelines for granting money. Most foundations and grantors require specific and detailed information regarding a project’s goal, concrete objectives, evaluation plan, and plan for ongoing funding as part of their application process. (NHPCO Guidelines, 2002b, p. 22) This is one reason data collection and documentation of services is so important to a hospice.

Hospices often receive donations or develop planned giving programs as part of fund development. Sometimes these gifts are made specifically in appreciation for bereavement services provided. In these cases, it may be possible for these funds to be specifically allocated to the hospice bereavement program. However, family members should not be directly solicited (through the mail, by phone, or in person) for donations during the 13 months that they are in the hospice bereavement care program. (NHPCO Guidelines, 2002b, p. 22)

Data Collection

Medicare COP: 418.66 states a hospice must conduct an ongoing, comprehensive, integrated, self-assessment of the quality and appropriateness of care provided. The findings should be used by the hospice to correct identified problems and to revise hospice policies if necessary. (NHPCO Guidelines, 2002b, p. 20)

Completing an evaluation and measuring the outcome of all hospice bereavement services on an ongoing basis is a necessary component of providing quality care. NHPCO has identified “effective grieving” as a desired outcome for hospice services. Adequate evaluation of hospice bereavement services should drive program and service revisions as well as the development of new program components. (NHPCO Guidelines, 2002b, p. 20)

Many hospices conduct a survey of family members’ overall response to bereavement services (including the extent and adequacy of those services) at some point during the provision of services and at the completion of those services. Hospices also should secure evaluations at the completion of support groups, educational programs, children’s camps, and all other program components. It is also important to evaluate the effectiveness of the services and programs provided by the hospice bereavement program to determine whether the service/program component has made an impact and difference in the ability of the bereaved to cope with loss and change. This may be accomplished by using pre- and post-program evaluations (or self-assessments) and comparing the two or by asking the bereaved to identify specific positive changes that have occurred because of having participated in the service/program component. It is important to compile the results of evaluations used on an ongoing basis to enable the identification of program strengths, weaknesses, areas for revision, and opportunities to develop new services/program components to help family members cope with loss. (NHPCO Guidelines, 2002b, p. 20)

The hospice should collect performance and outcome data related to patient care and hospice functions. Data should be collected about patient’s and family’s needs, expectations, and outcomes related to: safe and comfortable dying, self-determined life
closure, effective grieving, and on the staff and volunteer’s opinion of the hospice program and what improvements could be made. (NHPCO Guidelines, 2002b, p. 20)

Any data collection attempt should ensure the privacy and confidentiality of all participants. (Renzenbrink, 2002, p. 10)

Without adequate data collection, most hospices cannot comply with foundation and grantors requests for specific and detailed information for funding as part of the application process.

Research

There are no regulatory requirements or recommendations regarding research. The field of bereavement research is complicated by the fact that the losses are varied: spouse, parent, child, relative, friend; sudden, expected; accident, natural, inflicted, self-inflicted. Cultural norms and religions beliefs are also part of the bereavement experience. It is a huge challenge to consider all these factors when conducting research. (Center for the Advancement of Health, 2003, p. 42)

Validating the effectiveness of bereavement care provided by hospices is essential. Hospice bereavement programs and the services they provide can be greatly enhanced by research efforts that focus on the experience and needs of bereaved persons. To date, there is little research in the field of grief and bereavement. Hospice bereavement programs should seek every opportunity to contribute to the field by participating in research efforts that will assist professionals in the assessment of bereavement needs and the provision of services that will address those needs. Professional accountability suggests that we be able to “quantify” the benefits derived from receiving bereavement services. (NHPCO Guidelines, 2002b, p. 27)

Bereavement professionals should be aware of the current body of knowledge and practice in the field of grief, bereavement, and loss as well as research projects that are being conducted in the field. Hospice bereavement professionals should advocate for education and research to further knowledge about grief, loss, and identification of the most effective interventions to facilitate healthy coping. (NHPCO Guidelines, 2002b, p. 7)

NHPCO and its National Council of Hospice and Palliative Professionals are resources for consultation about past and current research projects. Colleges and universities are resources for assistance in designing and implementing a research project and may supply graduate students to do much of the background and quantitative aspects related to the research. Information about research and bereavement care practice on a national and international level is available on the Internet. In addition, many professional practice organizations publish journals that contain research articles that provide ideas for further exploration and development. (NHPCO Guidelines, 2002b, p. 27)

When conducting research, patient rights should be upheld and informed consent be obtained. A thorough review should take place regarding all possible ethical issues inherent in the research. Hospices should utilize an institutional review board to review research proposals to guarantee the rights of subjects involved. (NHPCO, Guidelines, 2002b, p. 27) The bereavement support program should ensure the privacy and confidentiality of all participants. (Renzenbrink, 2002, p. 10)

In early 2000, the research department of the NHPCO working with the National Council of Hospice and Palliative Professionals Bereavement Professional Section
identified a proposed research agenda for hospice bereavement care. The agenda poses five key questions to be answered:

- What do grieving people need?
- Who is at risk for poor outcome?
- How do we measure the impact of grief?
- How do we effectively support grieving people?
- What is the human “cost” of grief?

An additional research question was identified by the Center for the Advancement of Health (2003, p. 59, 61):

- Who should provide care for bereaved people?

Physicians, nurses, clergy, social workers, and hospice volunteers can and do provide bereavement care. However there is no empirical evidence that identifies who is most effective or cost efficient in providing bereavement care.

I would add another research question: what types of education and training are needed to provide effective bereavement support.

There is little in the way of established research that indicates the “best” type of bereavement services to provide, when the services should be provided, whether these services really benefit the bereaved, and who should provide the services. Best Practices for bereavement programs should be developed at a national level and provided to hospices.

**While grief is fresh, every attempt to divert only irritates.**

*Samuel Johnson (1709–1784)*

### Historical Hospice Surveys

In 1978, just 4 years after the first U.S. hospice was established in Connecticut, the General Accounting Office (GAO) surveyed 132 hospices (59 existing and 73 planned) by telephone. This survey determined basic information on licensing, funding, and staffing but did not determine the types and quantities of services the hospices normally provided. Most hospices did not have detailed information on the number of times they provided a service. (Buckingham and Lupu, 1982) The lack of data will be a recurring trend.

In addition, in 1978, the National Hospice Organization (NHO) surveyed 150 U.S. hospices. The information gathered was limited to a basic description of services, licensing, contracts, composition of staff, and population base served. A subsequent survey by the NHO of 20 hospice programs representing different models of hospice care gave more detail on planning, delivery of services, accreditation, and financing, but was again limited in scope. (Buckingham and Lupu, 1982)

**Buckingham and Lupu**

Buckingham and Lupu (1982) reported on a 1980 survey of 96 hospices included in the National Hospice Organization (renamed the NHPCO in 2000) Directory of Hospices in the United States. The survey provided limited information about bereavement care in the U.S. Hospices at that point in time did not evaluate the effectiveness of any programs or services delivered. The survey found most hospices
needed to improve program documentation because quality and effectiveness could only be supported by accurate information on hospice services. Most of the hospices could not provide complete information about the demographic characteristics of their clients and could not give breakdowns of funding sources or budget allocations. The survey concluded that formal evaluation of the quality of services and of success in attaining hospice goals would be essential to the development of future funding, regulating, and quality assurance policies. This will be a recurring trend found in other surveys. For more detailed information about this survey, refer to the Survey Details section in the Appendix.

NHO and Lattanzi-Licht Survey

In 1986, twelve years after the first U.S. hospice was established, Marcia Lattanzi-Licht collaborated with Boulder County (Colorado) Hospice in surveying 439 members of the National Hospice Organization concerning bereavement services. The Haworth Press published the results in 1989 in “Bereavement Care: A New Look at Hospice and Community Based Services.” This was one of the most detailed early surveys conducted on hospice bereavement services. Lattanzi-Licht (1989, p. ix) stated that while bereavement care was an important value and a differentiated characteristic to hospices, it had received scattered attention and the allocation of minimal resources.

Assessment - One of the goals and standards of hospice bereavement care involves the assessment of high risk factors among bereaved hospice clients. Most surveyed hospices used a risk assessment tool, usually one developed in their own hospice. Parkes’ Risk Assessment was used by a few hospices. A number of hospices indicated their assessment process was informal or a matter of discussion and judgment of the interdisciplinary team.

There was little bereavement service to high-risk clients; both personal contact with high-risk clients and support to high-risk clients ranked low. For a more detailed discussion of grief and bereavement risk factors, refer to the Discussion of Grief, Bereavement, and Risk Factors section in the Appendix.

Bereavement Services - Lattanzi-Licht found that the size and number of deaths per year influenced the type of bereavement services offered by a hospice program. The most frequent bereavement services provided were phone calls and visits by bereavement personnel or the nurse involved before the death. The next most frequent bereavement service was letters or notices about meetings or groups and literature and materials on grief. Most hospices offered group meetings and conducted memorial services. Other bereavement services were correspondence on grief, courses or group series, and a newsletter. Very few hospices provided individual bereavement counseling or had clients who sought or were referred to outside counseling. A few hospices offered social gatherings, seasonal cards, and a men’s bereavement group.

The survey questioned respondents about the type of bereavement services they would offer if time and money were not limitations. Most hospices wanted more groups, a dedicated bereavement coordinator, more staff coordination, more regular visits, more personal counseling, more educational programs, more mailings, additional resources such as books, pamphlets, and films, and a team of bereavement volunteers.

Budget and Funding - An average of $13,014 was budgeted for bereavement services with a range from $50 to $90,000. The bereavement budget averaged 7% of the
total hospice budget. Funding pressures was cited as the third most significant obstacle to providing bereavement services.

Data Collection - Only 40% of the respondents were collecting bereavement data (usually statistics, demographic data, and consumer surveys).

Research – Only 6% of the hospices were participating in any research activities. Lattanzi-Licht found the diversity and unique nature of a hospice’s bereavement service paralleled the unique nature of grief and the individual personalities of hospice programs. The person coordinating the bereavement services program and the interests of the staff and leadership of the hospice determined the delivery of bereavement services. In addition, the nature of the community also helped define the nature of the hospice program and its services. (Lattanzi-Licht, p. 22-23)

More detailed information and tabulated survey results are in the Survey Details section in the Appendix.

St. Mary’s Hospice - Arizona

In 1993, Alice Longman surveyed 56 members attending St. Mary’s Hospice bereavement programs in Tucson, Arizona. St. Mary’s bereavement program included one to one counseling by telephone, individual office visits, home visits, and two community programs. A Grief Support Group met weekly providing immediate support and a Life After Loss Group was for those at least three months after the death. The two-year study was to determine if the community programs were effective in assisting bereaved persons. Longman’s study found participants in the hospice bereavement programs believed the programs were beneficial. Through the groups, participants were able to resolve their feelings about the loss and they had a greater reliance on themselves. (Longman, 1993, p. 172-173) This is one of the few surveys that dealt with the effectiveness of bereavement services.

NHWG Survey

In 1997, the National Hospice Work Group (NHWG), a think tank and professional coalition of executives from some of the nation's largest and most innovative hospices, developed a formal written survey devoted to quality improvement processes to enhance the care of the dying. All NHWG hospices offered comprehensive services in both inpatient and outpatient settings to large urban, suburban, and rural populations in geographic regions or entire states. The responding hospices (N = 11) were all non-profit. At the time, the NHWG hospices cared for approximately 5% of all U.S. hospice patients with an average daily census of 42.5 patients. (D’Onofrio, 2001)

This was one of the few surveys dealing with program service quality. However, the statistics are small with only 11 responding hospices. Bereavement was the second most important focus for these hospices following achievement of a safe and comfortable dying. Actual quality results were not published, however, of the 11 responding NHWG hospices, 8 measured effective grieving, 5 measured bereavement counseling, 4 measured family stress reduction, and 3 measured bereavement assessment and bereavement contacts. Two measured death preparedness, spiritual assessment, and spiritual care.
NHWG and NHPCO Survey

Between 1998 and 2000, Ryndes, *et al.*, reviewed medical records of 22 hospice members of the NHPCO and The National Hospice Work Group (NHWG) to determine end result outcome measures in a large population of patients and families. They found that hospices begin dealing with grief issues from the time of referral or admission of the patient. Patients grieve the progressive loss of health and function and anticipate the loss of all things known to them, including relationships, hopes, and expectations. Primary caregivers, friends, and family members grieve the loss of the patient.

Two surveys were conducted: one survey at 2 months after the death and another at 13 months after the death. Of 1,739 respondents, 93% felt hospice had been effective in preparing them for the death and 95% felt hospice had been effective in helping them cope after the death. (Ryndes, *et al.*, 2000)

Hospice activities that led to these positive results included:

- Responding to grieving and coping dynamics that interfere with family functioning, including children in the family, and adhering to a plan of care and eventual grief resolution
- If high-risk behavior, uncomfortable coping, or complicated closure was found, hospice facilitated resolution of the immediate problem(s) and created a plan for appropriate follow-up
- Identifying a need for assistance with closure activities at the time of death or in facilitating final arrangements (mortuary, funeral, financial)
- Creating a notification plan for other providers of care, family, and friends
- Providing information about bereavement services offered
- Incorporating existing supports at school for ongoing needs of children in the family
- Encouraging and facilitating family access to their own support network such as friends and faith community
- Evaluating need for volunteer(s) to reduce family burden

(Ryndes, *et al.*, 2000, p. 57)

CHAP-CA Survey

In 1999, the California Hospice and Palliative Care Association (CHAP-CA) surveyed its 160 members regarding bereavement services. The response rate was 82% (N = 131). Donna Foliart, Margaret Clausen, and Cindy Siljestrom reported the results in *Death Studies*, “Bereavement Practices Among California Hospices: Results of a Statewide Survey,” in 2001.

Bereavement Services - While the survey found bereavement services variable, most hospices provided telephone support, sent scheduled mailings, and offered grief brochures to the bereaved following the death of a hospice patient. Pastoral care and visits from volunteers were the next most common bereavement service provided. Workshops and support groups were more often offered by large and non-profit hospices. Non-profit hospices tended to offer more programs for children and teens. Special holiday grief support, annual memorial services, and a “Grief in the Workplace” workshop were provided by several hospices. One hospice had a special fundraising
campaign to send children to summer bereavement camps. Another hospice funded its children’s bereavement program using grants.

**Budget and Funding** – Only a few hospices charged fees for bereavement support. Small fees were charged for some workshops, support groups (usually special support groups, children’s groups, widow/widower groups, and adult children support groups), and professional counseling. Fees were usually less than $50 or on a sliding scale. Fees were slightly more common among the larger hospices. A few hospices charged fees to community participants but not to families of hospice patients. Several hospices encouraged donations from participants.

More detailed information and tabulated survey results are in the Survey Details section in the Appendix.

**NHPCO - Demmer Survey**

In 2002, Craig Demmer adapted the Lattanzi-Licht survey and mailed it to a random selection of 450 members of the National Hospice and Palliative Care Organization (NHPCO). There was a 58% return rate (N = 260).

Demmer’s results, comparing the hospice bereavement services in the early 2000s with those in the late 1980s (the Lattanzi-Licht survey), were published in “Omega, Journal of Death and Dying” in 2003.

- **Assessment** - The number of hospices that used a high-risk bereavement assessment process increased over the number reported in 1986; however, most hospices still used a form of their own design.

- **Bereavement Services** - Fewer staff and volunteers were providing bereavement services in the 2002 survey than in 1986, even with the significant increase in the average number of deaths per hospice.

Bereaved individuals were most likely to receive letters or notices about meetings and groups, phone calls by bereavement staff, and literature and materials on grief. Fewer visits were reported than in 1986. This was probably related to not having enough staff or volunteers to provide this service, providing home visits to those with the greatest need as opposed to all bereaved individuals, or lack of interest from clients (Demmer, 2003, p. 338). There were also fewer group meetings and fewer memorial services.

Bereavement service priorities were literature and mailings, visits to the bereaved, support groups, and memorial services. Phone calls to the bereaved did not rate as high a priority as in the 1986 survey; however, it was one of the most common services provided in the 2002 survey. Referrals to outside therapists dropped in 2002.

Demmer found a number of innovative hospice bereavement programs had been implemented since the Lattanzi-Licht survey, including special support groups for grieving children, city-wide bereavement networks, use of volunteers (such as widows), grief recovery and anticipatory grief seminars, ongoing bereavement support, social support groups, volunteer speakers’ bureaus, and volunteer staffed bereavement teams. However, because there were still no specific state or federal standards on what constituted a hospice bereavement program, there was a great deal of variability in the types of bereavement services offered by hospices nationwide. (Demmer, 2003, p. 328)

If time and money were not limitations, most hospices would offer more groups, more educational programs, more home visits, more personal counseling, and additional resources (books, videos, and pamphlets).
**Budget and Funding** – Most hospices reported bereavement service budgets of less than 5% of the total budget. Financial support for bereavement services as a percent of the total budget had dropped since 1986 while number of deaths per year had more than doubled.

**Data Collection** - In 2002, most hospices were collecting bereavement data. This was a significant improvement over the number collecting data in 1986. Data collected in 2002 consisted of client satisfaction surveys, attendance in support groups, contacts with clients, number of clients receiving services, support group evaluations, and an annual survey of bereavement services.

**Research** - Only 8% of hospices were involved in research, similar to the finding in 1986.

Between 1986 and 2002, hospices became more established and had more seasoned bereavement programs. With a significant increase in average number of deaths a year, there had not been much expansion in bereavement staffing or budget. There continued to be a lack of standardized tools used to identify high-risk individuals. There also continued to be a mismatch between service priorities and actual delivery of service. While mailings and literature on grief was a top priority and the most commonly delivered bereavement service, support groups and memorial services were listed as a priority but were not offered as often by all hospices. Telephone support was not considered a top priority yet it was one of the most common services provided and there were fewer visits by hospice staff in the 2002 survey.

Demmer found there was a greater effort to collect bereavement data (though not detailed data) however, both surveys found few hospices involved in research. Lattanzi-Licht and Demmer encouraged hospices to participate more in research especially to document the effectiveness of bereavement services.

More detailed information and tabulated survey results are in the Survey Details section in the Appendix.
Hospice of Anchorage has been in operation since 1980. It is considered a community education and service resource for bereavement care. Services are available to anyone in need of support regardless of whether they or a family member received hospice services.

**HOA Compared to National Hospices**

NHPCO maintains a national data set on member hospices and issues summary reports periodically. The following discussion extracts general information and bereavement numbers from that database and the yearly reports. All numbers are averaged among the reporting hospices (around 650 in 2000, 900 in 2001, and 800 in 2002). (NHPCO, 2001, 2002a, 2004) Information about HOA was obtained from interviews with Julia Thorsness, Executive Director, and the Fall 2004 HOA Newsletter.

In 2002, most NHPCO member hospices were freestanding and not-for-profit hospices. Most hospices are in mixed locations or rural areas. Most hospice patients are located in private homes or in nursing homes. Hospice of Anchorage is a stand alone, private, urban, non-profit organization. By NHPCO standards, it is considered a small hospice, with 105 deaths in fiscal year 2004. While predominately urban, HOA does serve some rural communities through the Alaska Native Medical Center and through regular patient contact.

Cancer represents about half of the most prevalent hospice diagnoses nationwide followed by heart conditions. At HOA, cancer accounts for 73% of hospice patients (significantly higher than nationwide), followed by lung disease, heart disease, kidney disease, liver failure, ALS (amyotrophic lateral sclerosis), metabolic disorders, Alzheimer’s, and glioblastoma (malignant tumors of the central nervous system).

The demographics of the people who used national hospice services in 2002 are predominately White/Caucasian followed by African American and Hispanic/Latino. Most hospice patients are females older than 65. At HOA, females account for a patient population slightly lower than the national average. HOA has more Caucasian patients and fewer African American patients than the national average. HOA has about 3% Alaska Native clients and even fewer Asian/Pacific Islanders and Hispanics. Most of HOA’s clients are over 65 (55%); this is significantly lower than the nationwide clients over 65.

In 2002, nationwide, bereavement staff composed the smallest percentage of hospice staff (4%), the same percentage as reported in 2001. Clinical staff represented 67% of total staff. At HOA, there are five nurses (one takes evening calls), one social worker, one executive director, two bereavement coordinators (one is a volunteer with the Forget Me Not Children’s Bereavement Program), one development director, one office manager, and one medical director. While all staff provide bereavement support if needed, the dedicated HOA bereavement staff also represents a small percentage of the hospice staff, 2 out of 12 staff or 16%. However, this is significantly higher than the national average of 4%. Refer to the Hospice Statistics and Demographics section in the Appendix for more information.
Assessment - Hospice of Anchorage uses an assessment form designed in house (as found in the earlier surveys), but it does not cover many of the high-risk factors that NHPCO recommends be considered. Refer to the Bereavement Assessment Forms section in the Appendix.

Bereavement Services - HOA provides the following bereavement services:
- Phone calls, mailings, and visits by the bereavement staff and the RN involved with the patient before their death
- Correspondence on grief, letters and notices of groups and meetings
- Literature and materials on grief, a lending library
- Ongoing adult support group meets twice monthly
- Volunteer counseling, grief, bereavement and emotional support
- Memorial services, social events, healing art workshops, holiday grief programs (including the remembrance program between Thanksgiving and Christmas)
- Referrals to outside counseling and community agencies
- Educational seminars for the community and in-service for professionals
- Special teleconferences every April and local health fairs offer information and training on loss and bereavement
- Website that provides information about events, volunteer opportunities, and hospice resources

A bereavement coordinator focuses on children with outreach to and support for the local schools. Working with Life Alaska and the Children’s Hospital at Providence, HOA provides the Forget Me Not Grief Program, a children’s grief group. This is a facilitated peer support program for infants through teens and their parents or caregivers.

Working with AARP (American Association of Retired People) HOA provides Heart to Heart: AARP Program Offers Support. Bereaved persons can receive one to one support (phone calls or visits) from a bereavement outreach volunteer who has experienced a similar type of loss.

HOA works with other local organizations such as the YWCA, Senior Center, Alzheimer’s Group, Parents Reaching Out, the Asian community, all local hospitals, and with any group or business that requests loss or bereavement information or support. The organization participates in local health fairs to provide information about grief, loss, and bereavement.

HOA provides information on Alaska House Bill 25. (Prior surveys did not provide information relating to hospice and legislative bills or coordinating efforts between hospice and government entities.) Known as The Five Wishes, this bill is an act relating to health care decisions including do not resuscitate orders, the donation of body organs, and powers of attorney relating to health care. Bill 25 offers an alternative to the power of attorney enacted in Alaska in 1996 relating to health care services and directives for the terminally ill patient. It covers the details and instructions patients can put in place regarding their care should they become incapacitated. The Five Wishes are:
- The person to make care decisions for the patient when they can not
- The kind of medical treatment the patient wants or does not want
- How comfortable the patient wants to be
- How the patient wants other people to treat them
- What the patient wants their loved ones to know
In 2004, HOA collaborated with Providence Hospital to conduct an End of Life Conference and with the Alaska Native Medical Center to provide training and information on cultural issues surrounding bereavement. In addition, in October 2004, Remembering The Light was held at the Alaska Native Heritage Center. This was an evening event to acknowledge grief and loss in the community. Lanterns were made and set afloat in a special ceremony that featured dance and musical performances.

Budget and Funding – HOA does not charge for bereavement services. They provide care to individuals and families based on the need for services, not on the ability to pay. The Forget Me Not Children’s Program does request donations from the participating families, based on the family’s ability to give.

Currently, the bereavement budget is about 6% of the total hospice budget. Approximately 20% of HOA’s funding comes from United Way. Donations from individuals and groups make up 22%, memorials 11%, and special events such as the Remembrance Trees during the Christmas holiday season and garage sales account for the balance.

A volunteer Development Director has been used for the past two years to apply for various grants. A grant was received in 2004 from the Rasmuson Foundation to upgrade the technology system. Approximately 10 grants are outstanding. The organization would like to obtain approximately 10% of its funding from grants. To do this, they need a paid development director who can concentrate on applying for grants.

Data Collection - HOA does not participate in the data survey conducted by NHPCO because they survey is focused on Medicare certification criteria and HOA is not Medicare certified. They do track some demographic information about group makeup: age, gender, ethnicity, and number of and attendance at group meetings.

Research - Generally, HOA has one graduate student from the University of Alaska Anchorage working on some research aspect during a given year. In 2004, there were two nursing students working on projects: one on care giving of the chronically ill and one doing a five year review of the hospice program. Bereavement was a small part of this last project. My project on bereavement services is one devoted to bereavement.

Alaska Hospices and National Survey Results – A Comparison

The HOA bereavement program has been in operation for almost 25 years, since 1980 when the organization first started. The other Alaska hospices have been in operation from 14 months to 13 years, with an average of 7 years. There is an average of 105 deaths a year at HOA, slightly higher than the Lattanzi-Licht survey but significantly less than the Demmer survey. The other Alaska hospices reported between 4 and 110 deaths a year with an average of 40. Only Hospice of Mat-Su in Wasilla reported more deaths a year (110) than HOA.

Assessment

Adequate assessment is necessary within the hospice setting so that individuals are offered or can be referred to the appropriate level of service.
Lattanzi-Licht found 77% of the responding hospices used a risk assessment tool and 57.5% developed the assessment in their own hospice. A number of hospices indicated their assessment process was informal or a matter of discussion and judgment of the interdisciplinary team.

Demmer found 92% of the responding hospices used a high-risk bereavement assessment process; and 87% of the hospices still used a form of their own design.

Hospice of Anchorage uses an assessment form designed in house (as found in the earlier surveys), but it does not cover many of the high risk factors that NHPCO recommends be considered. Most of the other Alaska hospices use an assessment process developed in house and conducted by the social worker, the hospice team, or outside counselors. Denali Home Health and Hospice in Anchorage uses the Parkes-Weiss Assessment Scale.

Bereavement Services

HOA provides bereavement services to approximately 300 people a year. Children average 8 years of age; adults average 50 years. Three Alaska hospices reported older clients with average ages of 55 years, 68 years, and 70 years, with an overall average of 64 years. Gender is equal at HOA. Most other Alaska hospices reported more female clients than male; however, First Choice in Soldotna reported a ratio of about two males to one female. Most of HOA’s and the other Alaska hospices clients are Caucasian. Other ethnic groups served are Alaska Native, Hispanic, and Filipino.

Hospice of Anchorage provides the following bereavement services: phone calls and visits by the bereavement staff and the RN involved with the patient before their death; correspondence on grief; letters and notices of groups and meetings; literature and materials on grief; volunteer counseling; memorial services; social events; holiday grief programs (including the Remembrance Program between Thanksgiving and Christmas); and referrals to outside counseling and community agencies. These are similar services found in the Lattanzi-Licht and Demmer surveys. Holiday grief groups/support was not mentioned in the Lattanzi-Licht survey while counseling and correspondence was not mentioned in the Demmer survey.

New services provided by HOA are providing information about The Five Wishes and conducting healing art workshops. All the other Alaska hospices routinely provide
phone calls by staff, correspondence, and letters and notices of groups and meetings. Six hospices provide visits by staff and referrals to outside counseling as well as referrals to community agencies. Five hospices provide literature and materials on grief, memorial services, and holiday grief services. Four hospices provide courses or group series and pastoral counseling. Three hospices provide phone calls and visits by an RN, and distribute newsletters. Two hospices have social events. E-mail is used as a bereavement service by most of the Alaska hospices (a type of service not readily available in 1986). Services are provided to all who request them by all Alaska hospices, similar to the earlier surveys.

The Lattanzi-Licht survey found that if time and money were not limitations, hospices wanted more groups, a dedicated bereavement coordinator, more staff, more regular visits, more personal counseling, and more educational programs. Sixteen years later, Demmer found hospices still wanted more groups, educational programs, regular visits, and personal counseling; additional resources; and more salaried bereavement staff and volunteers. HOA has similar services it would like to provide: more groups (educational workshops and arts); regular visits and phone calls; more mailings (i.e. recognition of anniversaries, etc.); a regular newsletter; additional resources such as books, pamphlets, and films; a director for the children’s program; and more volunteers. Seven Alaska hospices would like more salaried bereavement staff. Five hospices would like a dedicated bereavement coordinator or more staff, more personal counseling, more phone calls to clients, more volunteers, and a regular newsletter. Four hospices would like more groups (groups for men, teens, youth, children, infants, and parents; groups dealing with infant loss, miscarriage, and suicide; and groups that met during the day), more regular visits, and more educational programs (bereavement counseling, grief in the workplace, care for the caregiver, living well with a loss, Alzheimer’s, suicide, and group
facilitation). Three hospices would like more mailings of inspirational and educational material. One hospice would like a Healing Center and a summer camp for children with grief.

### BEREAVEMENT SERVICES IF MONEY NO OBJECT

The chart below shows the preferences for additional bereavement services.

#### Budget and Funding

Lattanzi-Licht found bereavement budgets were on average $13,000, about 7% of the total hospice budget. Demmer found the bereavement budget had decreased slightly to less than 5% of the total budget for most hospices in 2002.

HOA’s bereavement budget is about 6% of their total budget. Some of the Alaska hospices have bereavement budgets ranging from $1,500 to $50,000. However, most of the other Alaska hospices do not have specific bereavement budgets or did not provide that information.

Including HOA, there are five hospices affiliated with United Way in Alaska. Alaska hospices raise money from United Way, individuals and groups, memorials, and special events (Holiday Light Up A Life or Holiday Remembrance Trees). Only one
Alaska hospice reported it was a for profit organization; however experience shows most home health hospices are for profit. There are four in Alaska.

Hospice of Anchorage provides all services without charge to hospice families (those who had a family member or friend receiving hospice care before their death) and community members in general and does not bill any insurance or government program. A charge for hospice bereavement services was not addressed in the Lattanzi-Licht or Demmer surveys. Hospice and Home Care of Juneau is the only Alaska hospice that indicated it charged for services. They charge $80 for an 8 week, 2 hour adult group and $20 a month for the every other week 1-hour children/family group. They also provide two free individual one-hour grief counseling sessions.

**Data Collection**

The Lattanzi-Licht survey found only 40% of the hospices collected bereavement data. This increased to 78% in the Demmer survey. Data collected in 2002 consisted of client satisfaction surveys (57%), attendance in support groups (38%), contacts with clients (26%), number of clients receiving services (13%), support group evaluations (12%), and an annual survey of bereavement services (8%).

HOA and one half of the other Alaska hospices collect bereavement data, however that data is still limited (mainly basic statistics such as age and gender, group attendance, income from memorials and special events, entrance and exit surveys, and community education training sessions required for grants).

Research

The Lattanzi-Licht and Demmer surveys found few hospices involved in research (6% and 8% respectively). None of the Alaska hospices are currently involved in research. HOA is currently working on a partnership with University of Alaska Anchorage (UAA) for possible research studies involving the children’s bereavement group.
Additional Items Discussed in the Survey

Who Provides Bereavement Services

Bereavement Coordinator is the title of the person coordinating bereavement services for HOA and it was the most frequently used title found in the Lattanzi-Licht and Demmer surveys. Most other Alaska hospices also used the Bereavement Coordinator title, sometimes with Social Worker or Director of Social Services.

One Alaska hospice uses the title of Hospice Director and Volunteer Coordinator. The HOA bereavement coordinator’s discipline is psychology (a discipline not listed in the earlier two surveys). The Lattanzi-Licht and Demmer surveys found social work as the most frequent discipline. Two of the Alaska hospice bereavement coordinators have social work and two have counseling as disciplines. One has education as a discipline and one is a layperson certified in massage therapy with bereavement training.

The HOA bereavement coordinator is salaried (similar to the earlier two surveys) and works 20-30 hours a week. She does work some volunteer hours. Most of the other Alaska hospice bereavement coordinators are also salaried; one is a volunteer and one is both salaried and a volunteer. The salaried coordinators work an average of 16 hours a week; the volunteer works an average of 10 hours a week. HOA utilizes approximately six volunteers working between zero and five hours a week per volunteer.

While all hospice staff can and do provide bereavement services, HOA has one dedicated staff person providing these services along with six volunteers (slightly more than found in the Demmer study, but much less than found in the Lattanzi-Licht study). Students are used occasionally at HOA. The other Alaska hospices have one staff person who works from 2 to 30 hours a week along with an average of 4.2 volunteers working from 3 to 8 hours a week. One of the other Alaska hospices uses a student for approximately 8 hours a week.
Bereavement Training

The earlier surveys found most hospices offered initial bereavement training of an average of 16 hours. The Demmer survey found about 65% of hospices offered additional training of an average of eight hours. HOA provides initial direct care training and approximately four hours of this training is dedicated to bereavement issues. Additional and continuing training is not routinely provided. HOA’s bereavement training hours are about 1/4 the bereavement training found in the prior surveys. The HOA Forget Me Not Children’s Program has 32 hours dedicated to bereavement issues. Most of the other Alaska hospices offer initial training from 1 to 30 hours. Hospice of Mat-Su trains in home volunteers through Mat-Su College.

For all the Alaska Hospices, initial training generally consists of personal death awareness and how it affects working with others, grief loss and transitions, the grief/bereavement process, listening and communication skills, providing support, and group facilitation skills. Hospice of the Central Peninsula in Soldotna provides additional training covering barriers to discussing death; the impacts of death on families; how families cope; interventions for normalizing death; increased coping skills; and boundaries and self care for helpers. In March 2005, Hospice of Haines offered a two day bereavement facilitator training to local teachers, counselors, and hospice volunteers with an emphasis on children, teens, and grieving families. 1st Choice Home Health and Hospice in Soldotna uses Hospice of the Central Peninsula in Soldotna to train their volunteers. This was the only example of hospices working together I found among the Alaska Hospices surveyed.

Obstacles to Bereavement Services

Lattanzi-Licht found the greatest obstacle to delivery of bereavement services was lack of sufficient staff time (30%). The second most frequently identified obstacle was lack of personnel (22%). Funding pressures (14.5%) was cited as the third most significant obstacle and staff or volunteer burnout was fourth at 10%. Other obstacles identified were complexity or difficulty in defining bereavement services (8.5%), lack of organizational support (8%), and insufficient training (5.5%).

As in 1986, Demmer found the top three greatest obstacles to the delivery of bereavement services were lack of sufficient staff time, funding pressures, and lack of personnel. In 2002, lack of interest of clients ranked fourth. Compared to 1986, staff or volunteer burnout, difficulty in defining bereavement services, lack of organizational support, and insufficient training did not change much in the rankings. A few hospices (8%) found it difficult to reach clients at home, a new category in 2002.

The main obstacles to HOA’s bereavement program are lack of staff time and lack of personnel (results similar to those found in the earlier surveys). Lack of client interest and reaching clients were categories that appeared in Demmer’s survey and in the Alaska surveys. The other Alaska hospices listed these obstacles in order of frequency: lack of staff time, funding pressures, lack of personnel, and lack of training. Two hospices listed lack of organizational support and difficulty in defining services as obstacles. Other obstacles were stress or burnout, lack of client interest; lack of adequate bereavement materials for mailings; problems with outreach to the community; family and community dynamics in a small, isolated Alaskan town; and people having a hard time associating bereavement with hospice services. For additional obstacles to hospice care, refer to Barriers to Hospice Care in the Appendix.
Web Sites
Three Alaska hospices have web sites: HOA, Hospice of Mat-Su in Wasilla, and Hospice of Tanana Valley in Fairbanks. This question was not part of the Lattanzi-Licht or Demmer surveys.

Referral Sources
Most Alaska hospices receive self-referrals and referrals from social workers, hospitals, and medical staff (doctors and nurses). Clergy, hospices in state or out of state, other family members, friends, and home health agencies are additional sources of referrals.

A tabular comparison of the Lattanzi-Licht, Demmer, Hospice of Anchorage, and the other Alaska hospice surveys are summarized in the Survey Details section in the Appendix.

Grief that is dazed and speechless is out of fashion: the modern woman mourns her husband loudly and tells you the whole story of his death, which distresses her so much that she forgets not the slightest detail about it.

Jean De La Bruyère (1645–1696)
DISCUSSION AND RECOMMENDATIONS

Alaska hospices continue to become more established and have more seasoned bereavement programs. The number of families, patients, and community members served depends on the number of referrals to the hospice, the familiarity of the community with hospice and the services provided, and the capability of a hospice to provide bereavement services which is directly related to staff size and budget.

The hospice concept has been in the United States for more than 30 years and in Alaska for more than 25 years; however, Alaska hospice bereavement programs continue to have few salaried full-time bereavement personnel, have small or nonexistent bereavement budgets, unsystematic training programs, and lack standardized assessment tools to identify high-risk individuals.

Some of the recommendations made below can be implemented on the local level. However, some should be considered on a national level to bring consistency and quality to all U.S. hospice bereavement programs.

Assessment

Alaska hospices use no definitive standardized risk assessment process. Most hospices continue to use an assessment form developed in house.

The existing HOA bereavement assessment tool addresses most of the areas mentioned by the NHPCO guidelines; however, it did not cover all areas. I prepared and recommended a revised assessment form incorporating the following items.

- **Informational**
  - Age and marital status
  - Length of involvement with hospice or community member
  - Was this person the primary caregiver for the deceased
  - Can messages be left referring to “hospice” either on the answering machine or with other family members

- **Physical**
  - Medical concerns for family members or significant others
  - Ability to take care of self and perform activities of daily living
  - Impairment of any kind, including substance abuse for self or family members
  - Change in sleeping or eating habits, stamina, energy levels, or appearance
  - History of physical illness
    - Name and phone number of current physician
    - Current medical problems
    - Current medications

- **Emotional**

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*Every heart has its secret sorrows, which the world knows not; and oftentimes we call a man cold when he is only sad.*

*Henry Wadsworth Longfellow*
• Ability to engage in emotional expression, able to tell the story of the death
• Feelings of loss, sadness, hopelessness, conflict, frustration, anger, irritability, guilt, self-reproach, anxiety, fear, denial, or depression
• Making plans for the future or has resumed former activities
• Suicidal thoughts and risk
  • Ideation or intent expressed
  • Plan or means considered
  • Prior attempts
  • Family or friends attempted
• History of mental health and/or psychiatric problems/intervention
  • Name and phone number of current therapist
  • Current medications
• Social
  • Degree of satisfaction with life closure tasks of patient/family prior to death
  • Support system
    • Family, friends or neighbors, church, community, co-workers, other (identify)
  • Cultural or ethnicity factors
• Spiritual
  • Degree of spiritual distress
  • Outlook, attitude, direction, and purpose of life
  • Meaning and value in life
  • Sense of “community”
  • Ability to access hope for the future
• Economic
  • Financial stability and debt burden
  • Problems with financial management or processing insurance claims
  • Dependents (children and others)
  • Employment
• Intrapersonal
  • Self-esteem, self-worth, self-confidence, and self-perceptions of competence
  • Ability to adapt to new roles/responsibilities
  • Personal strengths and weaknesses
  • Any other major stressors
• Risk Factors To Consider
  • Death was sudden or unexpected
  • Illness was very prolonged (2-3 years +)
  • Deceased was a child
  • Survivor felt death could have been prevented
  • Death was violent or traumatic
  • Past history of unresolved or multiple losses
• Relation with deceased was angry, ambivalent, or dependent
• Substance abuse
• Severe depression
• Suicidal ideation

Refer to the Bereavement Assessment Forms section in the Appendix for the existing and proposed bereavement assessment forms.

Bereavement Services
Bereavement services have not changed much since 1986. Phone calls, correspondence about grief and loss, visits by staff, individual counseling (by professionals or trained volunteers), memorial services, holiday grief programs, and letters and notices of groups and meetings remain the primary bereavement services provided by most national and Alaska hospices.

HOA has conducted healing art workshops (grief is expressed in art form using multiple forms of art media), provides information about The Five Wishes Alaska Bill, and uses e-mail to communicate with bereaved clients.

Existing bereavement programs seem to interest mostly older Caucasian females. Programs should be developed that would draw males and other ethnic groups.

Alaska hospices face similar obstacles to delivering bereavement programs as found in prior national surveys: lack of staff time, lack of bereavement personnel, and funding pressures. Refer to Barriers to Hospice Care in the Appendix.

Almost 20 years ago, Lattanzi-Licht (1986) identified several areas where hospice bereavement programs could improve. First, criteria, screening methods, time frames, and protocols should be established that allowed for maximizing the potential of telephone bereavement contact. Second, hospices should review their guidelines for referrals to outside counseling or psychotherapy. Referrals of persons needing intensive grief therapy or clinical intervention would allow hospices to concentrate on the majority of people who experience “normal grief.” Third, hospices needed to formally determine who will receive their bereavement services (including a definitive risk assessment process), set service priorities, and then devote time and resources consistent with those priorities. These items still need to be addressed by Alaska hospices today.

Budget and Funding
The value of services to an organization is often related to the budget dollars allocated to those services. To provide quality bereavement services (to both hospice families and the community at large), hospices should have adequate financial resources, especially since there is no avenue for collecting from Medicare, Medicaid, HMOs, private insurance plans, or other managed care organizations.

Ideally, there should be a budget with funds earmarked for the bereavement program. One of two budget formats could apply. A performance budget format emphasizes agency-activity performance objectives and accomplishments. This budget format focuses on activities, output, management, and efficiency. A program budget format organizes proposed expenditures according to output or contribution to the hospices objectives. This budget format focuses on achievements, outcomes, planning, and effectiveness. (Mikesell, 2003, p. 186-195)

Data Collection
Most prior surveys found hospices needed to improve program documentation because quality and effectiveness could only be supported by accurate information on
hospice services. Prior surveys concluded that formal evaluation of the quality of services and of success in attaining hospice goals would be essential to the development of future funding, regulating, and quality assurance policies (Buckingham and Lupu, 1982, p. 462). This holds true today.

Lattanzi-Licht (1989, p. 27) stated data collection and research were keys to continued exploration of the effectiveness and continuation of all hospice services. Yet in 1986, over 12 years after the hospice concept came to the U.S., few hospices were participating in either. This trend was found again in Demmer’s survey in 2002 and in the Alaska hospices surveyed in 2004.

Demmer found there was a greater effort to collect bereavement data in 2002 than in 1986; however, it was not detailed data on the bereavement services. All Alaska hospices need to improve program documentation because quality and effectiveness can only be supported by accurate information about hospice services.

Since HOA is not a Medicare certified hospice, it does not participate in the yearly data survey conducted by NHPCO because the survey focuses on Medicare certification criteria. A Family Satisfaction Survey is conducted after the death of a hospice patient. However, this has very little information about bereavement. The social worker informally collects information from volunteers as they process meetings with bereaved family members. Information is gathered from the staff annually at the time of the strategic planning session and at annual staff program planning sessions. Small volunteer groups have met periodically to provide feedback to the organization about programs.

To determine who actually uses hospice bereavement services and therefore what kinds of services to provide, detailed bereavement program information is needed. Tracking the following (including number, gender, and age) would greatly aid a hospice in determining what kind of bereavement services to offer, how, and when they should be offered:

- Clients/families served (hospice families and community)
- Assessments completed
- Visits and where visits occurred
- Clients/families using one to one counseling and referral counseling
- Group attendance (hospice families and community) and other special events
- Gender, ethnicity, and patient/family age ranges (0-5, 6-12, 13-19, 20-30, 31-49, 50-64, 65-74, 75+)
- Volunteers available, volunteers actually providing services, what kind of services are provided, attrition rate (how long they volunteer after training), and reason for attrition

I recommend HOA secure evaluations at the completion of support groups, educational programs, and all other bereavement programs. They are currently reviewing a family survey I obtained from NHPCO to use to provide feedback on bereavement programs. Refer to Evaluation of Hospice Care in the Appendix.

Research

Research and data collection are keys to continued exploration of the effectiveness and continuation of all hospice services yet few hospices participate in either. (Lattanzi-Licht, 1989, p. 27)
The following statement, made in 1984 by M. Osterweis and M. Green, editors of “Bereavement: Reactions, Consequences, and Care” (National Academy Press), still serves as a general indicator of the basic state of affairs in looking at bereavement outcome data that could be useful for hospice planning and budgeting:

Very little is known about the ability of any intervention to reduce the pain and stress of bereavement, to shorten the normal process, or to mitigate its long-term negative consequences. While the few controlled studies that have been conducted report contradictory findings, subjective reports attesting to the helpfulness of interventions abound. (Wrenn, et al., 2001, p. 180)

Bereavement research is complicated by the fact that the losses are varied: spouse, parent, child, relative, friend; sudden, expected; accidental, natural, inflicted, self-inflicted. Cultural norms and religious convictions are also parts of bereavement. (Center for the Advancement of Health, 2003)

Demmer and Lattanzi-Licht found few hospices involved in research. No Alaska hospices are involved in research. Both encouraged hospices to participate more in research especially to document the effectiveness of bereavement services. Universities, researchers, and private practitioners could initiate collaborative partnerships to promote bereavement research within hospice settings. (Demmer, 2003, p. 339)

Steele (1990) reported that the processes of grief and bereavement and the variables influencing their outcomes had been extensively researched for more than 20 years. Yet, there is still no theory that has enough empirical evidence to adequately explain or predict the outcome of bereavement or to prescribe appropriate interventions during the dying process that may positively influence bereavement outcomes. Research has described and identified the need for such services. However, there has been little research that identifies the effectiveness of social work, spiritual counseling, and bereavement services. (Oliver, 2003, p. 920, 924)

What constitutes “best practices” in hospices providing bereavement care to individuals and families in the period immediately preceding and following a death has not been defined. It is difficult for bereavement services to develop unless they are based on carefully thought out policies and procedures that set a clear direction and tone (Renzenbrink, 2002, p. 6).

Hospice research could focus on the following:

- Identify the effectiveness of social work, spiritual counseling, and bereavement services
- Develop “best practices” for hospices providing bereavement care to individuals and families
  - Determine the “best” type of bereavement services to provide, when the services should be provided, who should provide the services, and who should receive the services
  - Determine the content and processes of interventions that are likely to be most effective in preventing health problems and promoting well-being in individuals at risk of poor health outcomes
- Develop screening methods, time frames, and protocols and include a definitive, standardized risk assessment process that allows for maximizing the potential of bereavement contact
- Establish guidelines for referrals to outside counseling or psychotherapy
- Develop effective and comprehensive bereavement training programs for hospice staff and volunteers
- Improve program documentation in individual hospices

Research is needed to determine whether and under what conditions or circumstances bereavement interventions are indicated, or not, for individuals and families experiencing uncomplicated grief and to determine the content and processes of intervention that are likely to be most effective in preventing health problems and promoting well-being in individuals at risk of poor health outcomes. (Genevro, 2003, p. 76-78)

**NHPCO Guidelines for Bereavement Care in Hospice**

These guidelines were published in 2002 to provide a framework for bereavement care, however the bereavement coordinator of HOA did not have a copy. In December 2004, I conducted a benchmarking exercise with the bereavement coordinator using the guidelines to see how the organization rated. I provided the organization with written documentation of the outcome in addition to a complete copy of the guidelines. Due to the size, this exercise is not included as part of this project.

**Bereavement Coordinator Job Description**

The HOA bereavement coordinator did not have a job description outlining her responsibilities and functions. I provided her with a copy from the NHO Operations Manual.

**Training Material**

Parts of this project, specifically the discussion of grief and bereavement, barriers to hospice care, and hospice history and timeline of development are being reviewed for possible inclusion in the volunteer and training programs.

**Resource Material**

With a few exceptions, the hospices in Alaska do not communicate with or work with each other to provide bereavement care or develop bereavement programs or materials. There are only ten hospices in Alaska, nine with bereavement programs. I prepared and supplied each hospice with a contact list identifying the hospice, address, phone and fax numbers, website (if there was one), bereavement contact person, and encouraged the hospices to work together to develop bereavement programs and share information on the programs they currently have. Refer to the Hospices in Alaska section in the Appendix.

I developed lists of hospice resources, national hospice, and affiliated organizations and provided that to the HOA bereavement coordinator. Copies are in the Appendix under Hospice Resources.

I updated the Volunteer Application and the existing Bereavement Flow. Copies are in the Appendix.

The HOA bereavement coordinator has an interest in using art and music to heal grief. I provided her with a copy of an article titled “Healing Grief Through Art” by Malinda Hill along with a “Grief Kit” I found on the Internet. The grief kit is a whimsical article about the kinds of items to include in a “first aid kit” to deal with grief.
Licensing, Educational, and Training Requirements

Hospice bereavement programs and services have limited federal and state requirements and are loosely defined by the various government organizations and regulations. Federal regulations do not specify educational and licensing requirements for bereavement and spiritual counselors. Effective and comprehensive training programs should be a priority. While most national and Alaska hospices offer initial bereavement training, few offered specific additional or ongoing bereavement training.

I recommend there be specific educational and licensing requirements with identified training and experience requirements for hospice bereavement providers. National hospice organizations such as National Hospice and Palliative Care Organization, American Hospice Foundation, American Board of Hospice and Palliative Medicine, Children’s Hospice International, Hospice Association of America, Hospice Foundation of America, Hospice and Palliative Nurses Association, National Hospice Foundation, National Hospice Work Group, and the Volunteer Hospice Network could develop these qualifications. Refer to Hospice Resources in the Appendix for a list and description of these national organizations.

Quality Improvement Measures

The National Hospice and Palliative Care Organization has noted that hospices should have measures to assess the effectiveness of all services, including social services. Outcome studies and quality improvement initiatives in hospices have resulted in some research and evaluation of hospice programs, however, little has been done specific to social work, bereavement, or spiritual counseling. (Oliver, 2003, p. 920) Resources for quality improvement are NHPCO; the Quality Review Bulletin Journal of Quality Assurance published by the Joint Commission for the Accreditation of Healthcare Organizations; The Hospice Journal, published by the Haworth Press; state hospice accreditation program management and surveyor staff; Medicare certification surveyor staff; state hospice organizations; and other hospice providers. (Kilburn, 1997, pp. 167-168)

Death is, for most of us, the most profound emotional experience we will ever have to deal with. There is no right or best way to grieve. Grief is an individual emotion that requires different approaches. Grieving is hard work. Hard work is less burdensome where there are others, like hospice, to lend a hand. Author Hal Borland once said, “No winter lasts forever; no spring skips its turn.” Death seems like an ending, a winter that will last forever. Healing, like the spring at the end of a dark, cold Alaska winter will come. The hospice symbol is a circle of joined hands. Grieving is less burdensome where there are others, like hospice, to lend a hand.

Winter is come and gone, but grief returns with the revolving year.

Percy B. Shelley (1792–1822)
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Quotes from:


Grief is a very antisocial state.
Penelope Mortimer

No one ever told me that grief felt so like fear.
C.S. Lewis (1898–1963)


