Quality of Life for Patients and Caregivers: Palliative Care Funding Opportunities

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Quality of Life for Patients and Caregivers: Palliative Care Funding Opportunities

A THESIS SUBMITTED

By

Edward Joseph Schaub

In Partial Fulfillment of the Requirements

For the Degree of

Master of

Nonprofit Administration

The University of San Francisco

June, 2007
Quality of Life for Patients and Caregivers:
Palliative Care Funding Opportunities

This Thesis written by
Edward Joseph Schaub

This Thesis written under the guidelines of the Faculty Advisory Committee and approved by all its members, has been accepted in partial fulfillment of the requirements for the degree of:

Master of Nonprofit Administration

at the

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Abstract

Development of the field of palliative care, which was nourished through extensive private foundation funding over more than a decade, has to some extent been stalled because of sharply reduced private funding, a lack of understanding by the general population, and the inaction of major institutions.

This study investigated the current state of palliative care funding efforts in the San Francisco Bay Area (the "Bay Area") and across the U.S. The individuals that participated in the research component of this study included palliative care experts and palliative care funders. Through two separate surveys and two interview groups their perceptions and opinions were recorded. Three Bay Area counties were used for the purpose of considering how palliative care might be advanced across one specific finite region – with the hope that resulting information would be applicable to other regions in the U.S.

Research data indicated that Bay Area patients and their families, in the opinion of survey respondents and interview informants, would benefit from the advancement of palliative care, and that existing organizational priorities, capacity, and mission statements are congruent with the advancement of palliative care. This research revealed that most Bay Area funders are not knowledgeable about palliative care or of its capacity to improve quality of life, and that they do not plan to make related grants. Expert opinions from around the U.S. indicated that this is also the case among funders in general. Yet despite these findings the field continues to develop, if not at a rate that matches the ability of palliative care to impact positively the quality of life for patients and their caregivers.

The study revealed that where palliative care is not advancing there are individual professionals, organizations, systems, and policies that continue to impede its development.
Study findings suggest that there is an ongoing need among the general public, healthcare professionals, healthcare organizations and healthcare funders to understand the emotional, spiritual, and psychological barriers to dealing with chronic illness and death. Interview informant data suggests that America’s ageist society, its general inability to deal with death in holistic and healthy ways, and its medical culture that equates death with failure, regardless of quality of life, are all part of a complicated situation that makes funding in this field less than attractive and less than a top priority.
Vita Auctoris

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Acknowledgments

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Introduction

In 1997 the Journal of the American Geriatric Society published the following “Statement of Principles,” which was endorsed by more than 40 senior citizen and healthcare organizations:

This long period of time marking the end-of-life points to the importance of having care that enhances relationships, supports family, assuages pain, respects spiritual growth, and otherwise generally supports having a good life despite the shadow of death. However, our care system does not yet do this well. Pain and fragmentation of care is commonplace, attention to function is unusual, and even recognition of the implacable fact of mortality seems elusive. We all have a stake in this care. All of us will die, and most of us will have a long period of living with our fatal illness. That time is valuable and deserves attention (Lynn, 1997, p. 526).

One decade later this statement is appropriate as a description of the problem that the field of palliative care addresses. Yet the origin of the statement – the American Geriatric Society – might cause some to feel a bit uncomfortable because, they argue, palliative care serves an increasingly broad range of patients beyond seniors, including children and adults of every age. They might explain the struggle to have palliative care recognized across the field of medicine and across the general population – not only in the realm of hospice and geriatrics, and not only at the end of life. They would probably argue that hospice and palliative care are not one and the same, but rather that hospice falls under the umbrella of palliative care – that it is just one type of palliative care.. They might explain that although palliative care has to a large extent evolved out of the hospice model of interdisciplinary care, it has moved from the end-of-life
arena that is the focus of hospice. They might add that it has moved into the quality-of-life arena, and that its interdisciplinary approach can be used for patients at any point in the continuum of care – whether or not they have a chronic illness, a temporary one, or are facing death. At this point in the development of palliative care the refinement of such parameters and distinctions is the subject of much debate among those working in the field. What makes the statement relevant to the current field of palliative care is its focus on “the importance of having care that enhances relationships, supports family, assuages pain, respects spiritual growth, and otherwise generally supports having a good life,” in the face of illness, and its assertion that, “our care system does not yet do this well” (Lynn, 1997, p. 526).

The body of literature which focuses on palliative care provides a range of definitions that are worded in a variety of ways, but that generally include the information that is part of the definition that was adopted by the researcher for the purposes of this study. That definition is as follows: Palliative care is an interdisciplinary approach to care that seeks to improve the quality of life of patients and their caregivers. It is most often administered to those with a chronic illness or who are at the end of their lives. Pain management and support for quality of life play the central roles in this care, which is generally administered by a coordinated team of medical and nursing professionals, chaplains, social workers, and psychotherapists.

The dominant way in which it is different than hospice is that while hospice provides the interdisciplinary palliative care approach, it is focused on end-of-life patients. Palliative care is increasingly used to care for a broader array of patients, many of whom are not near to death, but who can benefit from it. It also increasingly works in tandem with curative care whereas hospice generally does not.
These issues set the frame for this study, which has explored the state of palliative care in the U.S., the significance and importance of its evolution as a field, the complex medical provider and payer universes it inhabits, the role that private funders have played in its expansion and evolution, and the simple, effective concepts on which it is built. They are to a large degree representative of the collective voice of the professionals the researcher heard from – professionals serving those in need of palliative care, those who understand “the importance of having care that enhances relationships, supports family, assuages pain, respects spiritual growth, and otherwise generally supports having a good life.” (Lynn, 1997, p.526).

Statement of Issue

A growing body of literature describes the suffering that occurs in the U.S. because of care delivery that is not appropriate, effective, or efficient. Research and demonstration projects in palliative care conducted over the last decade indicate that much of this suffering is not necessary, and that providing more effective and appropriate care can both reduce suffering and be more efficient. Alongside the research has been the growth of palliative care as a field, including the training of professionals and the establishment of programs. Still, experts argue that the field has not developed to the degree that is needed. A 2004 Wall Street Journal article (Naik, 2004) offered an explanation for this condition, saying that although palliative care is a standard practice in some nations, it has not been implemented to as large an extent in the U.S. because “. . . many doctors prefer to use the latest technology or drug to prolong a patient’s life, if only for a few months. Fewer than 20 percent of community hospitals in the U.S. use the approach [palliative care], according to the American Hospital Association” (p. A1). The

As palliative care increasingly addresses the needs of patients across the entire spectrum of age, one of the dominant reasons identified for the increasing urgency of more appropriate, effective, and efficient care at times of illness or at the end-of-life is the rapidly growing aged population. Doctors R. Sean Morrison and Diane Meier, who are both extensively published experts in the field of palliative care, described this in a 2004 article:

By 2030, 20 percent of the U.S. population will be over the age of 65 years. For most people, the years after the age of 65 are a time of good health, independence, and integration of a life’s work and experience. Eventually, most adults will have one or more chronic illnesses with which they will live for years before they die. These years are often characterized by physical and psychological distress, progressive functional dependence and frailty, and increased needs for family and external support. Studies suggest that medical care for patients with serious and advanced illnesses is characterized by the under-treatment of symptoms, conflict about who should make decisions about the patient’s care, impairments in caregivers’ physical and psychological health, and depletion of family resources. (p. 2582)

In the last decade the palliative care model has taken the hospice model further in addressing the type of concerns enumerated by Morrison and Meier; but hospice laid the groundwork for the field, starting with the founding of the first U.S. hospice in the early 1970s and continuing through the establishment of more than 2,400 hospices (National Association for Home Care & Hospice [NAHC&H], 2004, p. 2). Hospice has become an industry, has its own Medicare and Medicaid benefits, and is delivered in a range of manners in public, private, and
nonprofit settings. Yet, during those more than 30 years, changes in medical technology and medical culture apart from hospice and palliative care have significantly altered the way Americans die. Experts watching this evolution indicate that there are substantial negative repercussions tied to aggressive medical treatment that prolongs life, while decreasing the quality of that life. They argue that we have lost sight of the balance between extending life and providing for quality of life. They cite absence of education for patients, their caretakers, and families; medical professionals who, though they have extensive medical training, don't know how to deal with patients and their families in ways that are appropriate; and a lack of organized systems to support patients at such a difficult phase in their lives. Many healthcare professionals, hospices, hospitals, and other organizations have recognized the growing need for models that provide palliative care to a broader group of patients, in ways that are more flexible.

Palliative care models have been implemented at a number of institutions across the U.S., through funding provided by private foundations, through innovative financing, and through efforts of individual healthcare providers and professionals. However, while these models have been proven to be effective and efficient, to a large extent they have not been replicated elsewhere. In addition, over the last several years the two most prominent funders in this category – The Open Society Institute and the Robert Wood Johnson Foundation – have phased out their large-scale funding initiatives for this work (Perry, 2005). As a part of their exit strategies, and recognizing the gaps that would be left by their exits, both the Open Society Institute and the Robert Wood Johnson Foundation have provided significant models, funding agendas, and other information for funders who would like to continue the work that they started. However, preliminary review has indicated that other funders have not supported the palliative care models that emerged over the last decade to any large extent, and that the models have not
been implemented extensively across any region in the U.S., including the San Francisco Bay Area (the “Bay Area”).

It is fairly common knowledge that most foundations struggle to meet extensive demands with limited resources, and, just as importantly, that they struggle with having insufficient resources to create satisfactory impact in their existing focus areas. These factors often keep them from entering new fields. However, experts working in the development of palliative care programs and in palliative care advocacy argue that palliative care could enhance the current efforts of many funders, helping them achieve deeper impact in their current focus areas, and that even modest amounts of funding can implement proven palliative care interventions. It may also be true that funders in America avoid work in palliative care because it most often involves the unpleasant realities of traumatic illness or the last stages and the end of life, and because it involves treatment that is not aggressive in the style that America prizes. America’s ageist society, its general inability to deal with illness and death in holistic and healthy ways, and its medical culture that equates death with failure, regardless of quality of life, are all a part of a complicated situation that perhaps makes funding in this field less than top priority.

Will the work that was started by the Open Society Institute and the Robert Wood Johnson Foundation continue without them to any significant degree? Was the impact they made significant enough to play the role that foundations often play, initiating change that lasts once they exit the fields where it would not likely have occurred otherwise? By the end of its large-scale funding initiatives, the Robert Wood Johnson Foundation had contributed approximately $150 million for end-of-life and palliative care projects; and the Open Society Institute approximately $45 million (Perry, 2005). An article published in the Chronicle of Philanthropy in 2005 quoted Susan Block, the chief of the division of psychological oncology and palliative
care at Harvard Medical School: “We don’t have the kind of resources we had before. We’re hoping that other philanthropists, and particularly the government, will step up to the plate to make sure patients get the kind of care they deserve” (Perry, 2005). The call to action is representative of those of her peers at projects across the U.S. It also represents a real challenge and opportunity for the field of health grantmaking.

**Statement of Purpose**

This study provides a brief overview of the development and current state of palliative care in the U.S. It discusses palliative care funding options and related palliative care models available that have proven to be effective in the U.S. It references the work of the Open Society Institute, the Robert Wood Johnson Foundation, and institutions that are currently working in this emerging field of healthcare.

The primary research component of the study focused on the state of palliative care as described by palliative care professionals and funders from around the country. It also focused on three San Francisco Bay Area counties (Alameda, San Francisco, and San Mateo), including a non-exhaustive survey of existing healthcare institutions that provide palliative care or are primed for such work. This research elicited information from the perspectives of donors who work in these three Bay Area counties. All of these focus areas were selected with the hope of gathering information that could be used by funders already working to advance palliative care or by those who might consider it.

To that end, brief recommendations were developed in the following categories: (a) palliative care funding proven to be effective at sites across the U.S.; (b) existing opportunity in
the three Bay Area counties revealed through the primary research of the study; and (c) the predominant thoughts that emerged from the surveys and interviews.

Figure 1, delineates the research problem addressed in this study with several of the primary research questions.

<table>
<thead>
<tr>
<th>Context</th>
<th>Problem</th>
<th>Problem</th>
<th>Question</th>
</tr>
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<tbody>
<tr>
<td>30+ years of hospice and development of palliative care</td>
<td>End of the two major grant initiatives that brought extensive advances and change, leaving gaps and unfinished work</td>
<td>Existing policy, establishment and administration continue to impede palliative care development across U.S.</td>
<td>What knowledge and perceptions of palliative care, and of opportunities in palliative care exist among SF Bay Area healthcare professionals?</td>
</tr>
<tr>
<td>10+ years of research and practice in palliative care outside &quot;usual&quot; hospice work</td>
<td>Some palliative care programs struggle to survive, dissemination and implementation of proven models slows</td>
<td>Implementation of palliative care across regions has not taken place</td>
<td>What knowledge, perceptions, and compatibility with priorities is there among SF Bay Area philanthropic professionals and institutions?</td>
</tr>
<tr>
<td>Resulting significant reductions in patient and caregiver suffering</td>
<td>Heavy pressure placed on philanthropy to fill gaps left by end of major initiatives</td>
<td>Current priorities, gaps, best strategies, and opportunities for grantmaking across regions are unknown</td>
<td>What do palliative care experts and funders perceive to be current priorities, gaps, and best funding opportunities in palliative care?</td>
</tr>
<tr>
<td>$200 million of funding for palliative care over 10+ years through two major foundation grant initiatives</td>
<td>Gaps and proven models represent opportunity for foundations, but opportunity remains largely untapped</td>
<td>SF Bay Area knowledge, opportunities and potential strategy for palliative care development are unknown</td>
<td></td>
</tr>
<tr>
<td>Extensive advances and emergence of palliative care field</td>
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Figure 1. Delineation of problem and statement of questions
Chapter One: Review of Literature and Delineation of Problem

The literature review component was guided by the ultimate objective of the study: the gathering of information that will benefit citizens throughout the U.S. and in the Bay Area through identification of funding opportunities in the field of palliative care. While each region is unique, much of the research conducted for this study was oriented to the field of palliative care in general. The researcher’s assumption is that many of the lessons that have been learned at palliative care program sites around the country can be of use to Bay Area palliative care efforts, and that much of what has been learned through the Bay Area-specific elements of this study can be generalized for use at other sites in the U.S. and, potentially, in the international arena. Regarding the Bay Area-specific research, the researcher’s assumption is that many of the findings indicate funding opportunities that potentially exist elsewhere.

Performing the literature review enabled the researcher to gain understanding of the current state of efforts and trends in the advancement of palliative care in the U.S., previous efforts, tested practices, and past and current grantmaking efforts in the field of palliative care. The review examined the sparse published information available regarding palliative care and its funding in the Bay Area, and identified how gaps in information could be filled through the input of those working in the healthcare industry, in healthcare funding, and in related fields in the Bay Area and beyond.

Over a period of approximately one year the researcher used key words and concepts to search for relevant journal articles, government documents, website materials, books, and other publications. The predominant search engines used were ProQuest, PubMed, Ignacio (the online catalogue of the University of San Francisco’s library holdings), and Google. The researcher also gathered recommendations on literature and other pertinent information through
professional contacts made while working as a foundation program officer. Key information was also gathered by the researcher while being trained as a hospice volunteer caregiver, and subsequently while providing direct care to the chronically ill and dying in a palliative care and hospice unit.

As noted above, Bay Area information was sparse. However, extensive holdings existed in nearly every other category that the researcher used for conducting the review. The predominant categories were the following:

- San Francisco Bay Area hospices
- San Francisco Bay Area region palliative care
- Diseases and conditions indicating palliative care
- Family caregiver needs for those providing care for the chronically ill and dying
- Foundation support for palliative care and/or hospice
- General information and statistics concerning palliative care and/or hospice
- Medicaid/Medi-Cal benefits for hospice and/or palliative care
- Medicare benefits for hospice and/or palliative care
- Non-profit/for-profit palliative care organizations and/or hospices
- Palliative care policy movement
- Palliative care patient needs
- Private payers for hospice and/or palliative care
- Palliative care and/or hospice professional caregiver needs
- Education in palliative care and/or hospice
- Education in managing chronic disease
- Education in managing pain

10
Review of Literature

Palliative Care and Hospice in the New Millennium

To explore palliative care, its evolution and current state, and to understand the context in which it exists, it is essential to understand the evolution of hospice in the U.S. Palliative care evolved to a large extent out of hospice, yet hospice is now considered by many working in palliative care to be just one type of palliative care. Examples of non-hospice types of palliative care include: palliative care provided to those with a chronic illness, but who are not at the end of life; and palliative care that is provided to children simultaneously with curative care, which is not permitted through the hospice benefit. The researcher has observed that there is debate about the relationship between palliative care and hospice, and about the semantics involved, but not about the fact that they are related and somewhat interdependent.

Although hospice care in the U.S. began in the 1970s, the Medicare Hospice benefit was not created by Congress until 1982 (NAHC&H, 2004). At that point, Congress stipulated that reimbursement would be provided only to those who were terminally ill and with life expectancies of six months or less. In 2001 hospices served 579,801 Medicare patients (p.2). Data gathered in 2002 by the U.S. Department of Health and Human Services indicated that Medicare accounted for about 70.2 percent of the national hospice expense (p. 3), which means that Medicare dictates to a large extent what is possible in hospice and palliative care in the U.S. An estimated 2.2 percent of all Medicare benefit payments for all types of services and expenses went to hospice in both 2003 and 2004: $5,879,000 in 2003, and $6,466,000 in 2004. In comparison, payments for general hospital care totaled about 40 percent of Medicare payments in both 2003 and 2004 (p.4). Top revenue sources noted by palliative care programs included Medicare hospice benefits, Medicare non-hospice benefits, all Medicaid, health management
organizations, and preferred provider organizations (Pan, Morrison, Meier, Natale, Goldhirsh, Kralovec, et al., 2001, p. 319).

Hospice palliative care is generally administered by an interdisciplinary team that includes physicians, nurses, medical social workers, therapists, chaplains, counselors, home care aides, and volunteers. Pan et al. (2001) describes the practice in this way: “Palliative care seeks to improve clinical care of patients who have serious or life-threatening illness, to extend hospice philosophy to many patients and families who currently do not have access to hospice, and to train clinicians and health profession students to practice high-quality end-of-life care” (pp. 315-316). While hospice palliative care has advanced significantly and is used to a larger degree than ever before, much of the literature available indicates that healthcare professionals have grown increasingly frustrated with the Medicare hospice benefit which limits their ability to offer palliative services earlier in the progression of their patients’ diseases – especially for those with an illness that will be terminal, but who are not very near to death, or for whom no precise prediction of length of life can be made.

Hospice and palliative care have shown great potential for contributing to more cost-effective operations, when compared with the costs of standard hospitalization and care given at skilled nursing facilities. Studies on cost-effectiveness of hospice conducted by private organizations and by the government indicate that because hospice is less costly than other forms of care, earlier enrollment in hospice means that patients generally use the most expensive services less and net costs are lower (Beresford, Byock, & Twohig, 2002). A recent journal article, “The Growth of Palliative Care Programs in U.S. Hospitals,” discussed research based on American Hospital Association data that revealed significant reductions in direct and indirect costs, “associated with hospital palliative care compared to conventional care” (Morrison,
The article explained that these results had been consistent across a range of hospital settings, a range of demographics, and clinical service delivery models (Morrison et al., 2005). It is clear that earlier introduction of palliative care would mean less suffering, higher quality of life for patients, and more efficient systems of healthcare delivery.

Users of hospice are predominantly elders, most of them 65 or older. They are as likely to be men as women, and most of them are white (NAHC&H, 2004). The predominant diagnoses for Medicare hospice benefit users has gradually shifted over the last 25 years from predominantly cancer to about half cancer (Hogan, Mahoney & Kaplan, 2001). A number of variables influence choices about whether and when to begin hospice services, including physician practices and preferences, patient preferences and circumstances, and general awareness (or lack of awareness) of options among professionals and the public. Part of the work of recent palliative care efforts across the country has been to set standards and provide processes and techniques for the administration of appropriate and effective palliative care (Morrison & Meier, 2004).

While palliative care as a recognized discipline in the U.S. has only developed fairly recently, it has developed rapidly, and significant amounts of research, information, and resources are available. Again, this is due in large part to the extensive work of private foundations, most notably the Open Society Institute and the Robert Wood Johnson Foundation. The discipline has advanced to the point that journal articles now relate the need for palliative care programs complete with highly developed infrastructure, as illustrated in this passage from Meier & Beresford (2005): “If palliative care teams undervalue their contribution by failing to insist in advances on the level of infrastructure support required to run a quality clinical service,
they threaten effectiveness of their work with patients as well as the long-term survival of the service” (p. 1092).

Another area of focus that has emerged in the field is the need for greater support for non-medical caregivers. Research conducted in four teaching hospitals regarding the stress that family members or friends experience while caring for elderly patients (the largest group requiring palliative care) indicated that caregivers tended to be female and 50 years of age or older. About one in five of these caregivers described her own health as fair or poor, nearly half of them lived with the patient, about one quarter spent at least eight hours a day caring for the patient, and they had few persons available to help them with care (Desbiens, Mueller-Rizner, Virnig, & Lynn, 2001).

The predominant professional caregiver need that has been identified is for physicians. This includes education targeting communication skills and techniques, and concerning palliative care, its benefits, recertification, and reimbursement (Morrison & Meier, 2004).

Reimbursement is obviously an ongoing point of focus for those working in the field. Several documents reviewed during this research mentioned potential change in the administration of the Medicare Hospice Benefit. A report issued by the U.S. General Accounting Office (GAO) in 2000 states: “Palliative care is changing, as are notions of a decent or ‘good’ death free from unnecessary suffering for patients, families, and caregivers. New medical technologies and treatments are expected to result in better management of symptoms of chronic conditions and at the same time will blur the lines between curative care and palliative care” (U.S. General Accounting Office [GAO], 2000, p. 1). This is an interesting and important statement coming from the GAO, as it is an acknowledgement that the worlds of palliative care and hospice are changing and that “some patient advocates, hospice providers, and others
contend that certain Medicare beneficiaries for whom hospice care is appropriate may have
difficulty in gaining access to care or receiving services in a timely manner” (GAO, 2000, p. 1).
However, the report goes on to explain that officials of the Health Care Financing
Administration “and others assert that the hospice benefit is basically working as intended and
meeting the needs of those who choose to use it” (p. 1).

The same report by GAO states that about 360,000 beneficiaries enrolled in 1998, more
than twice the number in 1992. It also indicates that more patients are choosing hospice closer to
death, with half of those using Medicare enrolling for 19 or fewer days. This short-term use of
hospice care is commonly understood among those providing hospice care to be caused by
physician practices, patient preferences and circumstances, and lack of understanding among
professionals, patients, and their families. Advocates of hospice explain that hospice care can
best be delivered when it is started earlier, but for understandable reasons sick and dying
individuals and their families don’t want to call in hospice until they have to. Most people
associate hospice with the end of their life or giving up, and are reluctant to move in that
direction until they absolutely must. There is concern that doctors do not do an adequate job of
encouraging or educating patients so that they get the services as soon as they need them. In
some cases doctors and other providers are reluctant because of lack of understanding of benefit
parameters, or because federal oversight has negatively influenced them. The GAO report
acknowledges that federal oversight of eligibility “may have had an effect on beneficiaries’ use
of services” and that because of federal regulations, providers are more reluctant to admit
patients with non-cancer diagnoses (GAO, 2000, p. 8). A review of the Centers for Medicare
and Medicaid Services website (www. cms.gov) indicated no impending changes specifically
related to the hospice benefit; however, three demonstration projects appear to be related. They are titled as follows:

1. Demonstration Project for Consumer-Directed Chronic Outpatient Services (Centers for Medicare and Medicaid Services, 2003)
2. Medicare Care Management Performance Demonstration (Centers for Medicare and Medicaid Services, 2005)
3. Medicare Health Care Quality Demonstration (Centers for Medicare and Medicaid Services, 2005)

Initial examination of available details for the three projects indicated that there is some connection to the predominant concerns that have been raised concerning inability of physicians and institutions to provide appropriate treatment. However, no mention was made of the hospice benefit. Nonetheless, the extensive focus on the need for change in the way palliative care is delivered through the Medicare benefit suggested that it will continue to be a top issue for healthcare advocates. The review of these CMS documents and much of the other literature that was a part of the literature review, helped the researcher to form a perception that Medicare is closer to the tipping point toward significant changes in hospice and palliative care benefits than it has ever been.

*Market and Policy Drivers: Palliative Care and Hospice Payers*

The complex array of payers involved in the financing of healthcare has resulted in a variety of policies. This section of the review outlines some basic details about Medicare and Medicaid as payers, and about private payers. It also briefly covers policy that has resulted because of reimbursement systems.
Medicare and Medicaid control the field of hospice (and the field of palliative care, to the extent that it is dependent on the Medicare and Medicaid hospice benefits) because they are the predominant payers. For example, patients dying of serious nonmalignant diseases, such as congestive heart failure, often do not meet the prognosis requirement and thus do not qualify for the Medicare hospice benefit until very late in the development of the disease – although they have symptoms that indicate a need for palliative care long before they die. This illustrates how the hospice benefit is inflexible and dated. Congestive heart failure has become much more prevalent in the last decade (Lynn, Schuster, & Kabcenell, 2000).

Because of tight eligibility restrictions, many Medicare patients are shut out completely. Others, because of reimbursement policies, are forced to make the difficult choice between palliative or curative care, when they actually need both. This choice has come to be known as the “terrible choice” (Schapiro, Byock, Parker, & Twohig, 2003). Medicare reimbursement policies combined with uncoordinated care provided by multiple healthcare professionals and a medical culture that promotes preservation of life at all costs, has led to disjointed aggressive treatment as the norm. “It is often easier for a busy doctor to hospitalize a patient or institute treatment than to have an always difficult and poignant discussion acknowledging the possibility that the patient is dying, and discussing alternatives such as home care and hospice” (Beresford et al., 2002, p. 3).

Recent research by a collaborative team of policy scholars has shown that hospice costs are higher at the time of admission to hospice and at the time of death/discharge (Weisbrod & Lindrooth, 2004). During the first four to five days after admission there is greater cost due to learning about the patient, their needs, and those of their family. Per diem costs thereafter are generally low, up until about four to five days prior to death. At that point, bereavement
counseling and discharge arrangements generate higher costs. A U-shaped cost curve results, with high costs upon admission and discharge and low costs in between, which indicates that the longer the stay, the higher the profits. Some for-profit hospices have attracted patients who are likely to stay longer by offering services that are attractive to them; have discouraged those likely to stay only for a short period by not offering services that attract them; and have encouraged early admissions. The study determined that for-profit hospices have significantly larger shares of profitable patients than nonprofits, in part because nonprofits, in keeping with their mission, admit patients regardless of their profitability. While the researchers assert that more research is necessary to fully understand the implications of their results, they also indicate that their study demonstrates inefficiencies in the current reimbursement system (Weisbrod & Lindrooth, 2004).

The U.S. Department of Health and Human Services conducted a study to better understand the use of hospice benefits provided to those who are privately ensured (Jackson, Gibson, & Staeheli, 2000). The study, which included about 70 employers and 200 insurance carriers/claims administrators, revealed that there is a great deal of variation in the way benefits are designed. This includes, for example, variation in length of term for hospice/palliative care benefits; a great deal of variation in co-insurance and deductibles; and differing degrees of flexibility on guidelines. The study revealed three main approaches to design and administration of benefits:

1. Medicare-like Model: similar benefit periods and eligibility requirements, especially regarding the suspension of curative treatment.

2. Comprehensive Model: No suspension of curative treatment is required – curative and palliative care can occur simultaneously.
3. Unbundled Model – provides hospice service coverage for care unique to hospice, although with a lower lifetime limit than other models. Case managers are responsible for coordination of all care for terminally ill patient.

The study reports that “innovative approaches to end-of-life care have been uncovered” (Jackson et al., 2000) and lists case management of hospice services, combined palliative and curative treatment, and integration of hospice into managed care programs as innovative approaches. The authors also report that “Further study of how commercial plans are evolving their hospice benefit, especially their successes and lessons learned, may provide useful information to developers of programs to serve terminally ill individuals enrolled in all types of health care plans, including Medicare and Medicaid” (p. 4).

Jackson et al. (2000) found that only a minority of commercial plans adhere to the Medicare model, which participants described as “rule-bound, proscriptive” (p. 6). Most commercial plans, the authors say, seem to administer their hospice benefits “with a modicum of flexibility, accommodating the needs and desires of patients and families” (p. 7). The study claims that commercial plans can afford this flexibility because of the low demand for the service by covered populations, which are generally younger in age (Jackson et al., 2000).

The Jackson study leaves unanswered whether or not the commercial sector could play a much larger role than it has in leading the way to establishing benefits that meet the needs of patients, while at the same time meeting corporate financial targets. The literature review did not reveal examples of social enterprise models at work in the palliative care arena. There was some mention that traditionally business-oriented approaches could certainly serve the efforts of palliative care.
These findings reinforce the argument that smarter and more cost-efficient models are being created and implemented. Medicare/Medicaid and the masses of private payer organizations will continue to have a great deal of control and influence over the shape of the palliative care market and policies that dictate the parameters of palliative care delivery. Innovation in every sector will be essential to the development of more effective and efficient care delivery during chronic illness and at the end of life.

The Work of Foundations, Emerging Best Practices, and Where They Intersect

Efforts to develop and implement innovative models for the extension of palliative care are ongoing despite changes in the last five years in the funding provided by private foundations (Perry, 2005). A movement continues to solidify through a number of organizations that address these priorities and their partners working in the field. At the top of the agenda for such organizations is the development and dissemination of models proven to be successful, the implementation of training, and needed changes in policy (including Medicare hospice benefit reform). The Robert Wood Johnson Foundation (RWJF) has played a major role in this work, funding initial research on the critically ill in the 1990s and later funding a program to establish best practices and create model programs throughout the U.S. (Byock & Twohig, 2003). The RWJF program, now concluded, has incorporated small and large nonprofit organizations, university hospitals and medical schools, and private corporations. The grants have supported an extensive variety of projects that place a heavy emphasis on the measurement of impact and cost efficiency and the demonstration of successful models with the goal of stimulating a paradigm shift. The literature reviewed regarding the RWJF grants indicates that the dominant objectives expressed in the field were also the targets of the RWJF grants. While there is a great deal of
information beyond the RWJF program, the models and ideas expressed therein are among the
most well-documented available and can serve as good straw figures or starting places for the
advancement of palliative care services and related grantmaking in individual geographic
locations or across regions.

Much of the thinking on best practices and paradigm shift in palliative care is well
summarized in the following short list of targets, outlined by the National Consensus Project
(2004, p. 2):

- Pain and symptom control, psychosocial distress, spiritual issues and practical needs
  are addressed with patient and family throughout the continuum of care.

- Patients and families obtain the information they need in an ongoing and
  understandable manner, in order to grasp their condition and treatment options. Their
  values and goals are elicited over time; the benefits and burdens of treatment are
  regularly reassessed; and the decision-making process about the care plan is sensitive
  to changes in the patient’s condition.

- Genuine coordination of care across settings is ensured through regular and high-
  quality communication between providers at times of transition or changing needs,
  and through effective continuity of care that utilizes the techniques of case
  management.

- Both patient and family are prepared for the dying process and for death, when it is
  anticipated. Hospice options are explored, opportunities for personal growth are
  enhanced and bereavement support is available for the family (p. 2).

The RWJF program, “Promoting Excellence in End-of-Life Care,” which identified a
number of best practices in hospice and palliative care, was established to support the
development of healthcare systems and organizations that serve dying patients and their families. The program followed a 1995 RWJF commissioned study of 9,000 critically ill patients at five major medical centers in the U.S. (The SUPPORT Principal Investigators [SUPPORT], 1995). This research indicated that even though home care and hospice have grown significantly in the last two decades, most people die in hospitals, often alone and in pain. The program funded demonstration projects that tested innovative approaches to delivering palliative care with specific attention to cost and efficiency. The project demonstrated that appropriate levels of palliative care can be delivered efficiently (Byock & Twohig, 2003). Early reports on the program suggest that costs are the same or less than the costs of conventional curative care patterns which do not meet the needs of patients or their families.

Related to the work of RWJF, and what appears to be almost a response to the findings of the 1995 SUPPORT, that RWJF had commissioned, a 2004 World Health Organization report (Davies & Higginson, 2004) listed tangible goals for future palliative care policy. Among them:

- Identification of common serious diseases including cancer, ischaemic heart disease, cerebrovascular disease, chronic obstructive respiratory disease, end-stage liver and kidney disease, infectious diseases and dementia.

- Support for families and caregivers in their efforts to care for the patient and to cope with the sense of loss that the illness brings. This might include assistance similar to that often granted to those with maternity and paternity responsibilities.

- Services more widely and broadly offered and integrated across all health services.

- Services available on the basis of need in terms of symptoms and problems, and their effectiveness in meeting that need, rather than on the basis of diagnosis.
• Development of palliative care skills in staff working across all settings, especially in pain and symptom control and communication.

• Public education designed to increase awareness of palliative care issues.

(Davies & Higginson, 2004; also see Appendix A).

Funders Currently Working in Funding Palliative Care

At this point grantmaking in palliative care has been somewhat associated with the field of aging, and foundation support in the overall field of aging is significantly lower than that provided in other health and human service fields. For the categories of palliative care and hospice, a search in the Foundation Center data base revealed that in 2003 approximately $16,457,563 in hospice care grants were awarded and that approximately $12,750,463 in grants were awarded specifically for palliative care (Foundation Center, 2005). These amounts represent grants that run the gamut from general support for hospice care, to caregiver support programs, to healthcare worker training. The total amount for 2003, $29,208,026 (Foundation Center, 2005), is equal to about 1 percent of what Medicare spends annually, (based on the Medicare hospice expenditures reported for 2001 by the National Association for Homecare and Hospice (NAHC&G, 2004).

Approximately 20 funders have been identified by the affinity group Grantmakers in Aging as currently funding palliative care, hospice, or end-of-life care. Some of these funding agencies include:

• The Archstone Foundation, Long Beach, California

• The California Healthcare Foundation, Oakland, California

• The Colorado Trust, Denver, Colorado
• The Duke Endowment, Charlotte, North Carolina
• The Foundation for EOL Care, Miami, Florida
• The Hospice Foundation of America, North Miami, Florida
• The Jewish Healthcare Foundation, Pittsburgh, Pennsylvania
• The Robert Wood Johnson Foundation, Princeton, New Jersey
• The Rose Community Foundation, Denver, Colorado
• The New Jersey Foundation for Aging, Trenton, New Jersey

(C. Farquhar & Grantmakers in Aging staff, personal communication, 2006)

Several of these funders have recently announced new efforts in this field, among them the California Healthcare Foundation and the Archstone Foundation. Other funders have conducted extensive work in the field in the past, including the Kellogg Foundation.

Although it completed its work in this field several years ago, the Open Society Institute (OSI) made $45 million in grants to organizations and individuals working to improve care for dying patients and their families through its Project on Death in America. They exited the field leaving “Recommendations for Funders” in the following categories:

• Improvement of Professional Education
• Provision of Professional Education
• Building the Palliative Care Evidence Base
• Improvement of Direct Service Delivery and Clinical Care
• Work to Inform Public Policy
• Public Engagement and Education

(Open Society Institute, 2004, pp. 30-57)
Figure 2 is based on this and other information from the Open Society Institute and Robert Wood Johnson Foundation projects. It provides a summary from which current funders or those who wish to work in the field may size up their plans or develop their plans.

**Figure 2. Model for addressing gaps in care**

**Palliative Care in the San Francisco Bay Area**

A preliminary review of palliative care and hospice providers listed in the combined data from the California Hospice and Palliative Care Association and the National Hospice and Palliative Care Organization data bases, for the three Bay Area counties Alameda, San Francisco, and Santa Mateo, revealed 22 organizations. Fourteen of the 19 providers are nonprofit organizations, one of them is a government agency, and four of them are for-profit organizations. Eight of the 19 nonprofits have financial information listed on the GuideStar website (http://www.guidestar.org). See Appendix B for a complete listing of the organizations.
Because some organizations have listed themselves primarily as home health services, they do not always appear in documents as a hospice or palliative care provider. Consequently it is not certain how complete the listings provided by the two organizations are. Bay Area organizations involved in hospital-based palliative care work are not described in this section.

Although detailed information regarding hospices and the delivery of palliative care in the Bay Area was not readily available, extensive statistics and data for the nation regarding the existing baseline can be assumed to approximate what exists in the Bay Area. Best practices and program models developed over more than a decade have been implemented around the country at an array of organizations not unlike the Bay Area's organizations working in palliative care. Extensive national research can be generalized to indicate that problems similar to those existing in other parts of the country also exist in the Bay Area. Yet no significant research has been conducted to determine precisely what needs exist or whether models successfully employed in other parts of the country might be successful in the Bay Area.

**Summary of Literature and Implication for the Research Question**

Based on the review of literature conducted for the study, the reviewer found that:

- Patients and their families often don't understand or even know about choices in their care and treatment, when appropriate counseling and coordination of care could give them the capacity to make informed choices and ultimately lead to greater peace of mind
- Introducing palliative care earlier in an illness, along with life-prolonging treatment is linked to controlling costs
• Models of palliative care are viable and efficient, but are most often not fully implemented.

• Patients often die in hospitals who would rather die at home, which is something that palliative care can often provide.

• Patients often die in excruciating pain, when appropriate pain management through available protocols could make them comfortable.

Proven palliative care models, based on existing priorities in the field of palliative care and work underway at project sites around the country, could be replicated in the Bay Area. While not enough is yet known about Bay Area palliative care organizations, the need for the deployment of such models clearly exists, as it does in most regions of the U.S. Such development would have a major impact on the delivery of services and quality of life for those suffering from chronic illness that will eventually be terminal, and for those who are facing imminent death. Because such intensive preliminary research, development, and refinement has been conducted within the U.S. already, it can be estimated that the cost of implementation would be significantly lower than it has been for other sites and programs up to this point. Further investigation would be required to understand fully the potential for measurable impact and sustainability.

The literature search and review conducted for this study indicated that Bay Area organizations working in palliative care run the gamut from small one-shop nonprofit hospices that care for a limited number of patients, to large closed systems dealing with thousands of terminal patients, each year. What is not clear, based on the preliminary review conducted, is: (a) to what extent these organizations deliver palliative care; (b) what they have identified as problems and priorities related to palliative care needs and palliative care delivery; (c) what
financial and human resource capacity they have to do so; (d) what market exists for them to provide palliative care; (e) how conducive the delivery of palliative care is to their mission; and (f) how willing their boards, administrations, and staff members are to implement or advance palliative care work. It is also unclear to what extent funders who conduct work in the Bay Area have worked in, are considering, or would be willing to fund palliative care efforts. Finally, it is unclear to what extent funders are knowledgeable about palliative care or consider it to be a priority for healthcare in the region.

Regarding the broader fields of hospice and palliative care, deeper understanding of the RWJF projects and the work of the Project on Death in America is needed, especially regarding their quality of life impact, cost efficiencies and project sustainability, viability on a larger scale, the impact that they may have on Medicare and other policies, the extent to which other funders have continued the work they started, and the extent to which the projects and movement that they initiated have been sustained. While it would also be useful to uncover and understand other non-RWJF or OSI projects that are being conducted in palliative care development, the work of these two organizations alone may be the most central in making determinations about the possibilities for impact-oriented grantmaking.

Statement of Research Questions

Individuals and organizations were surveyed in an attempt to answer the following questions:

1. What knowledge and perceptions of palliative care exist in the Bay Area among healthcare professionals working in organizations where palliative care is or could be conducted?
2. What capacity, interest, demand, and barriers are present for the development of palliative care within Bay Area healthcare organizations where palliative care is or could be conducted?

3. What knowledge and perceptions of palliative care exist among philanthropic professionals at organizations that conduct healthcare grantmaking in the Bay Area?

4. To what extent is palliative care funding compatible with priorities and interests of philanthropic institutions that conduct healthcare grantmaking in the Bay Area?

5. What do palliative care experts perceive to be the current priorities, gaps, best strategies, best private funding opportunities, and best private funding strategies for the field of palliative care?

6. What do healthcare funders currently working – or who have previously worked – in the field of palliative care grantmaking (palliative care funder experts) perceive to be the current priorities, gaps, best strategies, best private funding opportunities and best private funding strategies for the field of palliative care?

**Definition of Key Concepts Investigated**

The key concepts and their definitions are as follow:

- **Knowledge of palliative care**: basic understanding of palliative care, including its principle components, and the ways in which it relates to hospice

- **Current work in palliative care**: any part of the range of work that is done in the field of palliative care, whether it be that which has been and is offered by hospices, recently developed palliative care models, or otherwise
• **Potential work in palliative care**: palliative care efforts that run the gamut described in the survey documents (from training for medical professionals to implementation of a complete palliative care program)

• **Barriers to work in palliative care**: economical, political, legal, personal or other potential reasons why palliative care work could not be implemented

• **Viability of palliative care development**: the degree to which the initiation, development, and execution of palliative care work is possible

• **Perceptions of cost effectiveness of palliative care**: the understanding or thoughts of participants regarding the potential economic benefit involved with administering palliative care programs

• **Perceptions of payer systems in relationship to palliative care**: understanding or ideas about the dependence of palliative care (and palliative care patients) on the organization that is paying the medical bill (and related policies and parameters)

• **Palliative care agendas**: the unofficial plans, next steps, and objectives for key organizations and sectors within the field of palliative care

• **Perceived priorities for the field of palliative care**: the things that any individual, from their vantage point, considers to be priorities for the field

• **Best opportunities in palliative care**: the smartest things to work on and invest in within the field of palliative care

• **Perception of leaders in palliative care**: thoughts of leaders from any of the core or peripheral positions in the field

• **Measurement of impact in palliative care**: the ability to measure and evaluate the outcomes of palliative care in qualitative and quantitative ways
How Research Question Will Contribute to the Field

The central objective of this study was that the resulting information and recommendations advance the efforts of funders and those seeking funds that were currently working in, or would potentially be working in, palliative care grantmaking and development. Ideally it will also be important to those using and administering palliative care and hospice services, especially in terms of making decisions to move forward with palliative care efforts based on funding possibilities, and in seeking out funding possibilities for such efforts. The hope is that the field in general will benefit in that a menu of funding options will be articulated.

The review of literature to date has demonstrated that no extensive research has been done to gather data and information on Bay Area palliative care and hospice delivery, its users, or its funders; nor does a significant body of information exist regarding palliative care efforts across any specified region in the U.S. This study will help fill those gaps, and in doing so provides evidence and insights with potential positive impact in the field.

The organizations and experts who participated will benefit from the research, attaining a higher level of understanding of their work, the field in which they are working, and of the opportunities for funding. This will be relevant to the work of participating funder organizations and experts and potentially to participating healthcare provider organizations and experts.

Information from the study will also benefit the educational efforts of the grantmaking affinity group, Grantmakers in Aging. While no specific mention will be made of any of the

- Geographical location: geographic location and/or scope of respondents
- Financial capacity: financial resources, flexibility, and ability to invest in palliative care of respondent’s organization
participating individuals or organizations, without obtaining their permission, general
information will benefit the development of a palliative care and end-of-life issue brief to be
published and distributed by Grantmakers in Aging to its members and potentially to others.

The study will benefit the social sector and nonprofit management field in that the
continuation of initiatives and projects in many different arenas (health-related and otherwise),
despite the withdrawal of major funding is an ongoing issue of concern. This points to the need
for understanding better possibilities and ways of thinking for social sector organizations, despite
the departure of major funders from any particular area. The study, while specific to palliative
care, demonstrates ways in which funders can tap into agendas and existing infrastructures
established by other funders.

Finally, and most importantly, the study contributes to the growing body of knowledge
that ultimately benefits patients suffering from chronic disease, and those who are at the end of
life, as well as their caregivers.
Chapter Two: Methodology

Design

Two exploratory surveys and an interview guide were designed to identify the interests, priorities, and knowledge of respondents, relative to the questions listed under Statement of Research Questions in Chapter One. The primary purpose of the data collection was to ascertain an understanding of levels of knowledge regarding palliative care and opportunities in palliative care that exist in one region of the U.S.; to assess the level of willingness among health care providers and funders in that region to consider work in this field. The data collected also helped the researcher understand trends in palliative care work and funding across the U.S. that have implications for work that might be conducted in any region within the U.S. Analysis of these data yielded observations and recommendations for those seeking funding options in palliative care. The analysis revealed that best practices and models proven effective at sites across the U.S. that would likely also succeed in the three Bay Area counties of focus and in other geographic regions.

Respondents

There were five groups of respondents, as follow: (a) current palliative care provider professionals working in one, two, or all of the three targeted Bay Area counties; (b) potential palliative care provider professionals working in one, two, or all of the three targeted Bay Area counties; (c) current healthcare funders who conduct grantmaking within one, two, or all of the three targeted Bay Area counties; (d) potential healthcare funders who conduct grantmaking within the three targeted Bay Area counties; and (e) experts in the fields of palliative care and/or palliative care funding.
Organizations and individuals were identified and invited to participate in the surveys based on the fact that they work in one of the relevant counties; and on the fact that there is some readily available evidence (through directories of professionals and professional services, through the internet, or other information) that indicates that the organization for which they work would potentially undertake efforts to advance palliative care; or that the organization had such efforts under way at the time of the research.

The first survey, “Healthcare Organization Survey,” was sent to identified executive directors (or other appropriate representatives) of healthcare organizations, including: hospitals (approximately 3 in each county, for a total of 9); home healthcare agencies (approximately 6 in each county, for a total of 18); nursing homes (approximately 6 in each county, for a total of 18); and hospice organizations (approximately 6 in each county, for a total of 18).

The second survey, “Foundation Survey,” was sent to identified appropriate program staff (staff responsible for work in this category or related categories) at foundations that the researcher perceived or found to be working in funding palliative care, or that were situated such that they could potentially do so: private foundations (approximately 4 for each county, for a total of 12); family foundations (approximately 3 for each county, for a total of 9); and community foundations (approximately 3 for each county, for a total of 9). (Note that while there are many unofficial classifications for grantmaking foundations, the two principle types are private and public. Private foundations are generally established with the funds of one individual, family, or corporation. One of the most common types of private foundation is the “family foundation,” which tends to be funded with resources from one family, be strongly influenced by that family, and which generally includes living donors and/or their heirs as board members or foundation executive or program staff. “Community foundations” fall into the realm
of public foundation and are required by law to receive funding from a diversity of sources, in
order to retain their public charity status.)

Interviews were conducted with individuals who were asked to participate based on their
expertise and/or experience as one of the following:

- medical professional
- non-medical palliative care team professional
- researcher in a related field (palliative care, hospice, end-of-life, etc.)
- foundation professionals who had administered funding or research into potential
  funding in the category of palliative care
- researcher/expert with extensive knowledge in payer issues (Medicare, Medicaid,
  private payers, etc.)

Twelve experts in the field of palliative care delivery and approximately 12 experts in the
field of palliative care funding were interviewed. Those invited were selected from an extensive
roster of experts identified in the course of the literature review. Also, in many cases the
researcher requested interviews based on existing relationships with experts that were formed
during the researcher’s professional foundation experience over the last several years. It should
be noted that prior to the research the researcher had exchanges in some cases in the form of non-
systematic interviews and/or conversations. These exchanges were conducted during the course
of the researcher’s professional experience, with no direct relationship to this study, but
concerning similar issues.
Operationalization of Concepts

Concepts identified for the research were operationalized through questions in the surveys and in the interview guide. The concepts identified in Chapter 1 are listed in Table 1. Questions from the surveys and interview guide (See Appendix C, Appendix D, and Appendix E) supported the research by eliciting information related to the stated concepts. The questions are all represented within this table by numbers which correspond exactly with the numbered items listed in the surveys and interview guide and aligned in rows with each concept for which they gathered information.

Table 1

Operationalization of Concepts

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<th>Expert interview guide questions</th>
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Table 1 (continued)

*Operationalization of Concepts*

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<tr>
<td>Perceptions of payer systems &amp; palliative care</td>
<td>15, 25</td>
<td>8, 9, 10, 11, 12, 14, 15</td>
<td></td>
</tr>
<tr>
<td>Palliative care agendas</td>
<td>15, 24</td>
<td>1, 3, 5, 6, 7, 8, 9, 10, 11, 12, 14, 15</td>
<td>12, 14, 15</td>
</tr>
<tr>
<td>Perceived priorities for field of palliative care</td>
<td>24</td>
<td>3, 6, 7, 8, 9, 10, 11, 12, 14, 15</td>
<td></td>
</tr>
<tr>
<td>Best opportunities in palliative care</td>
<td>16, 17, 24</td>
<td>3, 6, 7, 8, 9, 10, 11, 12, 14, 15</td>
<td></td>
</tr>
<tr>
<td>Perception of leaders in palliative care</td>
<td>24</td>
<td>5, 6, 7, 8, 9, 10, 11, 12</td>
<td></td>
</tr>
<tr>
<td>Measurement of impact in palliative care</td>
<td>24</td>
<td>9, 10, 11, 12, 13, 14, 15</td>
<td></td>
</tr>
</tbody>
</table>

37
Table 1 (continued)

Operationalization of Concepts

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Healthcare organization survey questions</th>
<th>Foundation survey questions</th>
<th>Expert interview guide questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geographic focus of participants</td>
<td>23</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Financial capacity of participants</td>
<td>23</td>
<td>11, 12, 13, 14</td>
<td></td>
</tr>
<tr>
<td>Type of organization</td>
<td>22</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

Each of the questions in the surveys and in the interview guide fell into one of the following classes: category scale questions, multiple response questions, or open-ended questions.

Some of the categories and issues referenced, and questions posed, in the Foundation Survey document were modeled after a survey conducted by the Archstone Foundation in cooperation with the national affinity group, Grantmakers in Aging. That survey, “End-of-Life Foundation Survey,” was conducted nationally by the Archstone Foundation during August of 2005 (Archstone Foundation, 2005). Though the survey was conducted nationally and focused on “end-of-life” grantmaking, some of the categories and issues referenced, and questions posed, are relevant to palliative care funding opportunity in the Bay Area context, and thus to this study.
A variety of materials and articles influenced the questions that were developed for Bay Area healthcare organizations, related to their existing or potential work in the field of palliative care. However, the three predominant influences in the development of these survey questions for the Healthcare Organization Survey were the Open Society Institute's Project on Death in America, the Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care, and the work of the Center to Advance Palliative Care to establish hospital-based palliative care programs (well documented in its publication *A Guide to Building a Hospital-Based Palliative Care Program* by Meier and Sieger, 2004).

**Procedures**

The two surveys and the series of interviews were conducted simultaneously over a period of three weeks. The first survey, "Healthcare Organization Survey" (HOS), was prepared for Bay Area healthcare organizations. The second survey, "Foundation Survey" (FS), was prepared for funders who worked in the Bay Area. The surveys were conducted using an internet survey service (Zoomerang.com). The organizations that the researcher identified for participation in HOS and FS were sent a hard copy introductory letter by U.S. mail requesting their participation in either HOS or FS. The letter indicated that they would receive a follow-up email within two weeks, which would once again invite them to participate in the survey, and which would provide an electronic link to the appropriate survey (through the Internet survey service Zoomerang.com). The letter explained how the researcher had identified them, and what the researcher's intended study would provide. It also made mention of the researcher's professional experience as a grantmaker working for private foundations, and of the researcher's affiliation with the grantmaking affinity group, Grantmakers In Aging. In addition, the letter
explained that the data would be used for the researcher's master's thesis and that results would be made available to them upon completion of the researcher's thesis, upon request. It also explained that, while they and their organization would not be identified, general information from the researcher's thesis would benefit a project that the researcher had underway with the grantmaking affinity group, Grantmakers in Aging. The project is a Grantmakers in Aging issues brief that provides an introduction to the fields of palliative care and end-of-life grantmaking for funders unfamiliar with these fields.

The researcher attempted to create surveys that were concise, easy to comprehend, and as intellectually stimulating as possible. The researcher tried to ensure that the questions were easy to answer, did not make respondents uncomfortable, and were not misleading. Extensive precautions were taken to protect the identity of participating organizations and to keep their information entirely confidential. Random numbers were used in place of participating organization names for purposes of data analysis. The researcher established a thorough system of controls for the data, including electronic files that required password information for access, and secured hard copy materials in a locked filing cabinet.

The researcher used one interview guide, "Palliative Care Expert Interview Guide" (PCEIG), prepared for use in all the interviews including those conducted with individuals whose area of expertise is delivery of palliative care and those whose expertise is palliative care funding. Semi-structured telephone interviews were recorded (with the consent of the experts) on a digital recording device. Interviews and notes from completed interviews were transcribed/recorded in Microsoft Word software.

The experts that the researcher identified for participation in the interviews were contacted by the researcher by email with a request for an interview to be conducted by
telephone at their convenience. The email messages explained how the researcher had identified
them or made reference to past collaboration or conversations, and stated what the researcher's
intended research would provide. The researcher also made mention of the researcher's
professional experience as a grantmaker working for private foundations, and of the researcher's
affiliation with the grantmaking affinity group, Grantmakers In Aging. In addition, the letter
explained that the data would be used for the researcher's master's thesis and that results would
be made available to them upon completion of the researcher's thesis. It also explained that,
while they and their organization would not be identified, general information from the
researcher's thesis would benefit a project that the researcher had underway with the grantmaking
affinity group, Grantmakers in Aging. The project is a Grantmakers in Aging "Issues Brief" that
provides an introduction on the fields of palliative care and end-of-life grantmaking for funders
who are not familiar with the fields.

None of the participating organizations or individuals were discussed in the thesis
manuscript by name or clearly identified without their prior consent. All organizations and
individuals mentioned by name in the manuscript were only mentioned in reference or
relationship to previously published information that is available to the general public through
literature, the Internet, or other media. In the analysis of data collected for the study, institutions
and experts were assigned a random number and categorized only by relevant type of institution
(home hospice, home healthcare, private foundation, family foundation, etc.) or expertise (health
care provider, researcher, etc.). All data files were password protected, and hard copies were
stored in a secure locked filing cabinet. All digital recordings were stored electronically and
password protected.

The interview guide was prepared with extensive care to ensure the most efficient and
effective use of expert time. Random numbers were used in place of participating experts’ names, for purposes of data analysis. To ensure the comfort of those being interviewed, the researcher briefly explained previous research and preparations for the interview. If the researcher sensed discomfort on the part of the expert being interviewed, the researcher gently reminded the expert that they were not required to answer any of the questions. Further, the researcher moved along to the next question, at any sign of discomfort on the part of an expert being interviewed. The researcher did not name or clearly identify any participating experts in the final thesis. The researcher established a thorough system of controls of the digital recordings and other data, which included electronic files that require password information for access, and secure locked storage of any hard copies of data.

Treatment of Data

Upon collection of the data from the survey service, the researcher sorted it by categories that the researcher established for the purposes of analysis (types of organizations, types of palliative care interventions, types of funding opportunities, etc.). Data were processed by the researcher, including necessary tabulation and data processing in Microsoft Excel and Microsoft Word software. Category scale questions were analyzed through preparation and study of frequencies and medians. Multiple response questions were analyzed through preparation and study of frequencies and percentages. Open-ended questions were analyzed for latent content. The analysis focused on frequency counts and percentages of the derived categories of responses.

Interview data were transcribed from recordings, and a coding structure was derived inductively from the data. Transcripts were analyzed, and once a system of qualitative and quantitative categories was established, data were entered into Microsoft Excel as necessary. Qualitative codes were analyzed by means of the researcher’s judgment.
Limitations

The sample was non-random and non-representative, and was not of sufficient size to allow the researcher to form definitive conclusions. In addition, many of the individuals interviewed were, by the nature of their work, strong proponents of hospice and palliative care work, which potentially biased their responses.
Chapter Three: Results

A total of 62 individuals participated directly in the research component of the project through two surveys and two series of interviews. This chapter presents the results of the surveys and the interviews, following a review of the initiating questions. The discussion of results is divided into four sections, which correspond with the four research methods employed for the study. The sections are as follow:

1. Survey One: Healthcare Organization Survey
2. Survey Two: Foundation Survey
3. Interview Group One: Palliative Care Experts and
4. Interview Group Two: Palliative Care Funders

Each of the four sections includes rates of response, description of the characteristics of the non-random, non-representative population studied, and specific findings.

Initiating Research Questions

The central questions that were addressed by this research are:

1. What knowledge and perceptions of palliative care exist in the Bay Area among healthcare professionals working in organizations where palliative care is or could be conducted?

2. What capacity, interest, demand, and barriers are present for the development of palliative care within Bay Area healthcare organizations where palliative care is or could be conducted?

3. What knowledge and perceptions of palliative care exist among philanthropic professionals at organizations that conduct healthcare grantmaking in the Bay Area?
4. Is palliative care funding compatible with priorities and interests of philanthropic institutions that conduct healthcare grantmaking in the Bay Area?

5. What do palliative care experts perceive to be the current priorities, gaps, best strategies, best private funding opportunities and best private funding strategies for the field of palliative care?

6. What do healthcare funders currently working – or who have previously worked – in the field of palliative care grantmaking (palliative care funder experts) perceive to be the current priorities, gaps, best strategies, best private funding opportunities, and best private funding strategies for the field of palliative care?

Survey One: Healthcare Organization Survey

Rate of Response

Sixty-five individuals were identified as potential respondents for the Healthcare Organization Survey (HOS), and introductory letters were sent to them, indicating that an electronic hyperlink to the survey would be sent to them via email. The emails were sent; 12 were immediately returned for nonfunctioning email address information; 24 surveys were completed, or partially completed, electronically via the Internet; and there was no response or communication to 29, whom it can be assumed received the email (because there was no indication that the email was not received). Of the 24 responses, 22 were used for purposes of analysis – two being excluding because they were almost entirely incomplete. The 22 responses (out of 65 requests sent) that were used for purposes of analysis provided a final valid response rate of 33.8 percent. The respondents that submitted completed surveys were the subjects for the Survey One section of the study (N=22).
Description of the Characteristics of the Organizations Surveyed

The respondents were a non-random non-representative sampling of the healthcare professionals who worked during the period of the survey (August of 2006) at healthcare organizations that served patients from the Bay Area counties included in this study. They worked for organizations that fall into one of the following four categories: (a) hospital; (b) home healthcare agencies; (c) skilled nursing facilities; and (d) hospice organizations.

The nine respondents who reported organization budget information indicated approximate organization annual budgets ranging from $850,000 to $33 million; six of the respondents reported not knowing their organization's annual budget. Twenty-three percent of the respondents indicated that palliative care is the focus of the organization for which they worked, and 32 percent that palliative care was a substantial part of the organization’s work (see Table 2).

Table 2

<table>
<thead>
<tr>
<th>Degree</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus of their work</td>
<td>23</td>
<td>5</td>
</tr>
<tr>
<td>Substantial part of their work</td>
<td>32</td>
<td>7</td>
</tr>
<tr>
<td>Plays small role in their work</td>
<td>45</td>
<td>10</td>
</tr>
</tbody>
</table>

Length of experience in palliative care work varied among the respondents. All of the organizations represented did some work in palliative care, with 32 percent of them working in palliative care for between two and four years, 27 percent of them from five to 10 years, and 32
percent for more than 10 years. Seventy-one percent of them identified their organizations that they work for as providing in-patient palliative care services, and 61 percent as providing palliative care consultative services; while only 23 percent described their organizations as providing palliative care outpatient services. There was a concentration of work, by specific type of palliative care, with 90 percent of the organizations working in expediting communication and decision-making, and 90 percent of them working to increase coordination among health care providers (see Table 3).

Table 3

| Current Palliative Care Work at Respondents' Organizations by Type of Work (N = 22) |
|-----------------------------------------------|---|---|
| Expediting communication and decision-making | 90 | 20 |
| Increasing coordination among health care providers | 90 | 20 |
| Pain and symptom control | 86 | 19 |
| Easing patient transitions between care settings | 86 | 19 |
| Promoting beneficial care, resulting in more appropriate use of hospital resources, cost avoidance, and improved palliative care capacity | 72 | 16 |
| Reducing the burden to improve staff satisfaction and retention | 50 | 11 |
| Applying systematic approach to outlier (long length of stay) patients | 27 | 6 |
Specific Findings

Findings represented in this section provided answers to the following initiating question: What knowledge and perceptions of palliative care exist among Bay Area among healthcare professionals working in organizations where palliative care is or could be conducted?

One hundred percent of the 22 respondents indicated that they have a “very clear” understanding of the difference between hospice and palliative care. The majority of them perceived existing medical systems to meet the needs of patients sometimes, while only 11 percent believed that existing medical systems always meet the needs of patients (see Table 4).

Table 4

*Perception of Existing Medical Systems Capacity to Meet Patient Needs* (N = 19)

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Existing systems always meet the needs of patients</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>Existing systems sometimes meet the needs of patients</td>
<td>89</td>
<td>17</td>
</tr>
<tr>
<td>Existing systems never meet the needs of patients</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
The majority of respondents believed that providing palliative care costs less than the care provided by the current dominant system, while only one quarter of them believed that palliative care costs the same or is more expensive (see Table 5).

Table 5

*Perception of Cost-Effectiveness of Palliative Care (N = 20)*

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Much more expensive than care provided by predominant systems</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Costs just about the same as care provided by predominant systems</td>
<td>20</td>
<td>4</td>
</tr>
<tr>
<td>Costs less than care provided by predominant systems</td>
<td>75</td>
<td>15</td>
</tr>
</tbody>
</table>
Seventy percent of the respondents believed that palliative care could be implemented within the parameters of current payer systems. Only 30 percent thought it almost impossible to offer palliative care within existing systems (see Table 6).

Table 6

*Perception of Interface Between Current Payer Systems and Palliative Care*  \((N=20)\)

<table>
<thead>
<tr>
<th>Perception of Interface</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care can work well within existing systems</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>With some maneuvering palliative care can work within existing Systems</td>
<td>60</td>
<td>12</td>
</tr>
<tr>
<td>Almost impossible to offer palliative care within existing systems</td>
<td>30</td>
<td>6</td>
</tr>
<tr>
<td>It is not possible to offer palliative care within existing systems</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
The respondents’ opinions on the viability of palliative care were based on knowledge of best practices in palliative care in the United States, which most of them claimed to understand a great deal, or at least to some extent (see Table 7).

Table 7

*Understanding of Recent Best Practices in U. S. Palliative Care Work (N = 20)*

<table>
<thead>
<tr>
<th>Understanding of Palliative Care Work</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Know a great deal about what has been done</td>
<td>60</td>
<td>12</td>
</tr>
<tr>
<td>Know that some work has been done</td>
<td>35</td>
<td>7</td>
</tr>
<tr>
<td>Sounds familiar, but don’t really know much about it</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Have heard nothing about it</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

The findings represented and discussed in the following paragraphs provided answers to the following initiating question: What capacity, interest, and barriers are present for the development of palliative care within Bay Area healthcare organizations where palliative care is or could be conducted?

Table 8 describes the general relevance of palliative care to the respondents’ organizations. Most of the respondents asserted that the populations served by their organization would benefit from a palliative care program (85 percent); that pain and symptom management show room for improvement at their organizations (71 percent); and that services currently provided by their organization could benefit from collaboration with a palliative care program (61 percent). A smaller, but still noteworthy, percentage of the respondents believed that a palliative care program could save their organization money (42 percent), and close to one third
believed that it could increase the organization's capacity to earn revenues (28 percent).

Twenty-eight percent believed that staff members experience stress related to their understanding (or lack of understanding) of treatment for patients with life-threatening illness.

Table 8

**Perception of Relevance of Palliative Care to Respondents' Organizations**

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organization has a patient/client population that would benefit from</td>
<td>85</td>
<td>18</td>
</tr>
<tr>
<td>a palliative care program</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain and symptom distress scores for patients with life-threatening conditions show room for improvement</td>
<td>71</td>
<td>15</td>
</tr>
<tr>
<td>Organization currently provides services that could benefit from</td>
<td>61</td>
<td>13</td>
</tr>
<tr>
<td>collaboration with a palliative care program</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A palliative care program could save the organization money</td>
<td>42</td>
<td>9</td>
</tr>
<tr>
<td>Palliative care program could increase capacity to earn revenues</td>
<td>28</td>
<td>6</td>
</tr>
<tr>
<td>Staff registers stress due to perceived understaffing for treatment of patients with life-threatening illness</td>
<td>28</td>
<td>6</td>
</tr>
</tbody>
</table>

52
The majority of the respondents indicated that palliative care supported or would support their organizations’ missions. None claimed that it would not support their organization’s mission (see Table 9).

<table>
<thead>
<tr>
<th>Degree Palliative Care Supports/Would Support Organizations’ Missions (N = 20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clearly supports mission</td>
</tr>
<tr>
<td>Though not primary to mission, it does support it</td>
</tr>
<tr>
<td>Does not support mission</td>
</tr>
</tbody>
</table>

Percent: 13, 7, 0
The respondents mostly perceived their organizations to be well situated or somewhat situated to develop collaborations. Few indicated that collaboration would be difficult, and none that it would be impossible (see Table 10).

Table 10

Perceived Capacity to Collaborate on Palliative Care \((N = 21)\)

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very well situated to develop collaborations</td>
<td>57</td>
<td>12</td>
</tr>
<tr>
<td>Somewhat situated to develop collaborations</td>
<td>29</td>
<td>6</td>
</tr>
<tr>
<td>Would be a stretch to develop collaborations</td>
<td>14</td>
<td>3</td>
</tr>
<tr>
<td>Not situated to develop collaborations</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Table 11 describes the top types of palliative care that respondents believed that their organizations would be interested in advancing. By far, the predominant items are pain and symptom management and increased communication at all levels.

Table 11

*Top Palliative Care Areas for Advancement at Respondents' Organizations*

<table>
<thead>
<tr>
<th>Area</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improving patient outcomes through expert pain and symptom control</td>
<td>90</td>
<td>19</td>
</tr>
<tr>
<td>Expediting communication and decision-making for patients, family members, and health care providers</td>
<td>61</td>
<td>13</td>
</tr>
<tr>
<td>Promoting beneficial care, resulting in more appropriate hospital resources use, cost avoidance, improved palliative care capacity</td>
<td>47</td>
<td>10</td>
</tr>
<tr>
<td>Increasing coordination among health care providers</td>
<td>38</td>
<td>8</td>
</tr>
<tr>
<td>Easing patient transitions between care settings</td>
<td>23</td>
<td>5</td>
</tr>
</tbody>
</table>
The specific focus areas that respondents identified to advance palliative care at their organizations, as listed in Table 12, support the findings related in Table 11, particularly regarding symptom management, training and education, and family caregiving.

Table 12

<table>
<thead>
<tr>
<th>Specific Areas to Advance Palliative Care at Respondents' Organizations</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom management</td>
<td>66</td>
<td>14</td>
</tr>
<tr>
<td>Training and education</td>
<td>66</td>
<td>14</td>
</tr>
<tr>
<td>Family caregiving</td>
<td>57</td>
<td>12</td>
</tr>
<tr>
<td>Advanced directives</td>
<td>52</td>
<td>11</td>
</tr>
<tr>
<td>Bereavement services</td>
<td>52</td>
<td>11</td>
</tr>
<tr>
<td>Collaborations</td>
<td>52</td>
<td>11</td>
</tr>
<tr>
<td>Direct services</td>
<td>52</td>
<td>11</td>
</tr>
<tr>
<td>Program evaluation</td>
<td>52</td>
<td>11</td>
</tr>
<tr>
<td>Therapies (massage, music, etc.)</td>
<td>52</td>
<td>11</td>
</tr>
</tbody>
</table>

The barriers to palliative care that respondents stressed, not surprisingly, were lack of financial resources and lack of human resources. While respondents indicated that they would not expect their board of directors or the mission of their organization to represent barriers, some thought that their organizations' administration would (see Table 13).
Table 13

*Barriers to Advancing Palliative Care at Respondents’ Organizations*

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t have financial resources</td>
<td>61</td>
<td>13</td>
</tr>
<tr>
<td>Don’t have human resources</td>
<td>52</td>
<td>11</td>
</tr>
<tr>
<td>Administration will not support it</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Board will not support it</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mission will not support it</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Even though 61 percent of the respondents indicated lack of financial resources as a barrier to advancing palliative care, when asked to rate their financial resources specifically, 33 percent claimed that their organization did have the financial resources and 43 percent claimed that it had some resources. Only 14 percent claimed that their organization had no resources to expand what they currently did in palliative care (see Table 14).

Table 14

Financial Viability for Advancing Respondent Organization Palliative Care (N = 21)

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Currently have the financial resources</td>
<td>33</td>
<td>7</td>
</tr>
<tr>
<td>Have some resources, but not enough to do what they would like to</td>
<td>43</td>
<td>9</td>
</tr>
<tr>
<td>Very few resources to do what they would like to</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>Have no resources to expand what they currently do</td>
<td>14</td>
<td>3</td>
</tr>
</tbody>
</table>
In terms of overall organizational capacity for advancing palliative care, 20 percent of respondents indicated that their organization had the needed capacity and 45 percent indicated that their organization had some capacity. Only 35 percent indicated that their organization had very little or no capacity (see Table 15).

Table 15

*Overall Capacity for Advancing Palliative Care at Respondents’ Organizations (N = 20)*

<table>
<thead>
<tr>
<th>Capacity Description</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have capacity</td>
<td>20</td>
<td>4</td>
</tr>
<tr>
<td>Some capacity, but not enough to do what they’d like</td>
<td>45</td>
<td>9</td>
</tr>
<tr>
<td>Very little capacity to do what they’d like</td>
<td>20</td>
<td>4</td>
</tr>
<tr>
<td>No capacity to expand what they currently do</td>
<td>15</td>
<td>3</td>
</tr>
</tbody>
</table>
Most of the respondents indicated that they were ready, or somewhat ready, to receive a grant to carry out a new project in palliative care. Only a combined 16 percent indicated that they would need to implement a number of things to carry out a new project – or that they could not be ready to carry out a new project (see Table 16).

Table 16

*Organization Readiness for New Grant-Funded Palliative Care Projects (N = 19)*

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well poised to receive a grant and carry out a new project</td>
<td>42</td>
<td>8</td>
</tr>
<tr>
<td>Somewhat ready to receive a grant and carry out a new project</td>
<td>42</td>
<td>8</td>
</tr>
<tr>
<td>Need to implement a number of things to receive a grant and carry</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>Section to receive a grant and carry out a new project</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Could not be ready at this time to receive a new project</td>
<td>5</td>
<td>1</td>
</tr>
</tbody>
</table>

Respondents perceived the expertise of their organization’s staff to be the area of strongest capacity for advancing palliative care, including medical, case management, and spiritual (chaplaincy) expertise. They also asserted that interest in palliative care based on personal or professional experience represented a type of capacity within the organizations, and that there was strong community and board interest in it as well. They stressed that there was currently significant expertise in pain management and that they were well equipped with capacity for electronic medical records (see Table 17), which facilitates the coordination and administration of cross-disciplinary care, as well as generally optimized care.
**Table 17**

*Existing Essential Capacity for Palliative Care  (N = 19)*

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>MD/RN clinicians with interest and/or training in palliative care</td>
<td>90</td>
<td>19</td>
</tr>
<tr>
<td>Relationships or contracts with other organizations that focus on palliative care</td>
<td>71</td>
<td>15</td>
</tr>
<tr>
<td>Case management</td>
<td>71</td>
<td>14</td>
</tr>
<tr>
<td>Chaplaincy program</td>
<td>90</td>
<td>19</td>
</tr>
<tr>
<td>Palliative care interest based on personal or professional experience</td>
<td>85</td>
<td>18</td>
</tr>
<tr>
<td>Pain services</td>
<td>52</td>
<td>11</td>
</tr>
<tr>
<td>Computerized medical records</td>
<td>52</td>
<td>11</td>
</tr>
<tr>
<td>Community interest in and support for palliative care</td>
<td>57</td>
<td>12</td>
</tr>
<tr>
<td>Trustee or board or philanthropic interest in palliative care</td>
<td>47</td>
<td>10</td>
</tr>
</tbody>
</table>
Respondents were very interested in learning more about palliative care (see Table 18).

Table 18

*Interest in Learning About Palliative Care (N = 20)*

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very interested</td>
<td>80</td>
<td>16</td>
</tr>
<tr>
<td>Somewhat interested</td>
<td>20</td>
<td>4</td>
</tr>
<tr>
<td>Not interested</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Survey Two: Foundation Survey

*Rate of Response*

Twenty-eight individuals were identified as potential respondents for the Foundation Survey, and introductory letters were sent to them, indicating that an electronic hyperlink to the survey would be sent to them via email. The emails were sent; four individuals responded with declinations via direct email communication; 16 were completed electronically via the internet; and there was no response or communication from eight, whom it can be assumed received the email (because there was no indication that the email was not received). Of the 16 responses, 15 were used for purposes of analysis (one being excluded because it was almost entirely incomplete). The 15 responses that were used for purposes of analysis provided a final valid response rate of 53.5 percent. These respondents were subjects for the Survey Two section of the study (N=15).
Description of the Characteristics of the Population Studied

The respondents were a non-random, non-representative sampling of healthcare funders who worked during the period of the survey (August 2006) at philanthropic institutions that made grants in the Bay Area. Nine of the respondents identified the philanthropic institution they worked for as a family, independent, or private foundation; four of them identified the philanthropic institution they worked for as a community foundation; one of them identified the foundation employer as an operating foundation; and two of the respondents did not make any indication of the type of philanthropic institution for which they worked. The foundations that employed these respondents all were currently making grants or had made grants in the three Bay Area counties studied, and they were predominantly located within those three counties. Two of the respondents worked for a philanthropic institution located outside of California. Respondents described the geographic focus of their grantmaking as depicted in Table 19.

Table 19
Geographic Focus of Philanthropic Institutions for which Respondents Work (N = 14)

<table>
<thead>
<tr>
<th>Geographic Focus</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regional</td>
<td>36</td>
<td>5</td>
</tr>
<tr>
<td>International</td>
<td>29</td>
<td>4</td>
</tr>
<tr>
<td>Statewide</td>
<td>21</td>
<td>3</td>
</tr>
<tr>
<td>Countywide</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Local</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>National</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Although not all respondents reported total asset amounts of their foundations employers, those who did indicated that the current asset values of their employers ranged from between approximately $1.5 million to roughly $6 billion, with the median value being $775 million. The median number of grants likely to be made by the represented philanthropic institutions during their current fiscal year was 155, with a range from 35 to 1,300. The median grant dollar amount to be expended by the foundations during their current fiscal year was $35 million, with a range from $850,000 to $230 million.

Respondents indicated a range of approximately 17 grantmaking priorities, the top two most common of which were access to healthcare, which was listed seven times; and reduction of health disparities, which was listed five times. The following priorities were all listed twice: chronic disease; hospital and skilled nursing facility capacity; nursing; policy/advocacy; prevention and education; and technology.
Specific Findings

Findings represented in this section provided answers to the following initiating question:

What knowledge and perceptions of palliative care exist among philanthropic professionals at organizations that conduct healthcare grantmaking in the Bay Area?

Most of the respondents indicated that they had some knowledge of palliative care, while very few indicated that they had a great deal of knowledge of palliative care (see Table 20). The majority indicated that they had some knowledge of recent palliative care work in the United States (see Table 21), but the majority did not have a very clear understanding of the difference between palliative care and hospice (see Table 22).

Table 20

Knowledge of Palliative Care (N = 15)

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comprehensive</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>A great deal</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Some</td>
<td>80</td>
<td>12</td>
</tr>
<tr>
<td>Very little</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>None</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Table 21

*Understanding of Recent Palliative Care Work in the United States (N = 15)*

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>A great deal</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Some</td>
<td>67</td>
<td>10</td>
</tr>
<tr>
<td>Not much</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>None</td>
<td>20</td>
<td>3</td>
</tr>
</tbody>
</table>
Table 22

*Understanding of the Difference Between Palliative Care and Hospice (N = 15)*

<table>
<thead>
<tr>
<th>Understanding</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very clear</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>Some understanding</td>
<td>67</td>
<td>10</td>
</tr>
<tr>
<td>Very little understanding</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>No idea</td>
<td>7</td>
<td>1</td>
</tr>
</tbody>
</table>
The findings represented and discussed in the paragraphs below provided answers to the following initiating question: What compatibility with priorities and interest is there for palliative care funding within philanthropic institutions that conduct healthcare grantmaking in the Bay Area?

The respondents indicated that they had made grants for direct services and skilled nursing facilities within the palliative care related grantmaking that they had conducted. To a lesser degree they had provided support for hospice, general operations, and training and education (see Table 23).

Table 23

Top Five Palliative Care Grantmaking Types at Respondent Organizations

<table>
<thead>
<tr>
<th>Grantmaking Type</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct services</td>
<td>45</td>
<td>5</td>
</tr>
<tr>
<td>Skilled nursing facilities</td>
<td>45</td>
<td>5</td>
</tr>
<tr>
<td>Hospice</td>
<td>36</td>
<td>4</td>
</tr>
<tr>
<td>General operations</td>
<td>36</td>
<td>4</td>
</tr>
<tr>
<td>Training and education</td>
<td>36</td>
<td>4</td>
</tr>
</tbody>
</table>

The majority of the respondents indicated that they would not make palliative care grants in the foreseeable future, or that they were uncertain whether or not they would, while about one fifth indicated that they would. Specifically, 67 percent indicated that they would not make palliative care grants during the current year; 20 percent said that they would make palliative care grants (the range of estimated grants in palliative care was between 3 and 22); and 13
percent said that they were uncertain whether or not they would make palliative care grants. Also, 80 percent indicated that they would not make grants in the categories of end-of-life or hospice; two of the respondents indicated that they would each make one grant in these categories; and one indicated that they would make 15 grants in these categories. These numbers suggested that Bay Area funders did not, for the most part, plan to make palliative care grants – or hospice or end-of-life grants – to any large extent.

In response to a question about what their focus for grantmaking in palliative care or end-of-life work (including hospice) would likely be if they were to make grants in one of those areas, only 10 of the respondents gave any answer. Fifty percent of those who responded indicated that they would support direct services, and 40 percent reported that they would support skilled nursing facilities. These potential funding areas, along with others that were highlighted to a lesser degree, are listed in Table 24.
Table 24

*Top Nine Categories of Palliative Care or End-of-Life Work Respondent Organizations Would Most Likely Support, if They Decided to Work in Either Category*

<table>
<thead>
<tr>
<th>Category</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct services</td>
<td>50</td>
<td>5</td>
</tr>
<tr>
<td>Skilled nursing facilities</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>Advocacy/awareness</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Collaborations</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Demonstration or pilot programs</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Family caregiving</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Leadership training</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Palliative care (general)</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Training and education</td>
<td>30</td>
<td>3</td>
</tr>
</tbody>
</table>
Respondent interest in learning about palliative care can be interpreted to indicate that there was not great enthusiasm for working in this category. As related in Table 25, below, only 7 percent indicated that they were very interested. The rest were only somewhat interested or not interested at all.

Table 25

*Respondent Interest in Learning About Palliative Care Grantmaking (N = 14)*

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very interested</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Somewhat interested</td>
<td>57</td>
<td>8</td>
</tr>
<tr>
<td>Not interested</td>
<td>36</td>
<td>5</td>
</tr>
</tbody>
</table>

Respondents did, however, indicate that if palliative care were to be a priority, that they would make their choices based to an equal degree on assessment of needs in the community and on their foundation's pre-established priorities. They also rated high, among decision-making factors, the opportunity to make a difference, the opportunity to capitalize on models proven to be effective, and the opportunity to inform public policy (see Table 26).
Table 26

*Top Five Factors that Would Influence Decision-making About Palliative Care*

*Grantmaking, if It Were a Priority*

<table>
<thead>
<tr>
<th>Factor</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment of need in the community</td>
<td>61</td>
<td>8</td>
</tr>
<tr>
<td>Foundation’s pre-established priorities</td>
<td>61</td>
<td>8</td>
</tr>
<tr>
<td>Opportunity to make a difference</td>
<td>53</td>
<td>7</td>
</tr>
<tr>
<td>Opportunity to capitalize on models proven effective</td>
<td>46</td>
<td>6</td>
</tr>
<tr>
<td>Opportunity to inform public policy initiatives</td>
<td>46</td>
<td>6</td>
</tr>
</tbody>
</table>

While the survey did not register a strong sense of the need for increased community awareness, two respondents did raise the issue: one regarding awareness of patients and their families and the other regarding awareness in the philanthropic community. Funder Survey Respondent 8 noted, “Definitions of palliative care and hospice care seem not clearly articulated. Would like to know how patients and their families are able to make decisions about them. What influences them?” Funder Survey Respondent 12 commented, “Educating the grantmaking community regarding issues pertaining to palliative care is paramount. This topic has not been discussed at the Bay Area Health Grantmakers Forum.”
Interview Group One: Palliative Care Experts

Rate of Response

Twenty palliative care experts were identified as potential informants for this interview group during the literature review process or through professional experience of the researcher during his tenure as a foundation program officer. Twelve of the 20 agreed to participate during the period in which interviews were administered, which provided a valid response rate of 60 percent. These informants were the subjects for the Interview Group One section of the study (N=12).

Description of the Characteristics of the Population Studied

The informants represented organizations that were identified primarily as follow: five hospital-based palliative care programs, two hospice organizations, one major multi-region healthcare organization, two organizations that advocate for palliative care, and one research institution. Most of these organizations were involved in one or more other focus areas. For example, the organization represented by one of the informants was considered first a hospital-based palliative care program, but it carried out a hospice function and conducted research. This provided perspectives from a variety of vantage points and regarding many facets of palliative care.

Five of the respondents' primary function in palliative care and/or hospice was practicing medicine as a physician; one practiced as a nurse, and two administered or coordinated programs. The primary focus for two respondents was research in or related to palliative care and/or hospice, and two others focused primarily on advocacy and support for those working in palliative care and/or hospice. However the respondents collectively represented a wide variety
of other professional expertise and involvement within the field of palliative care. Eight of the 12 identified themselves as being trained in medicine, with eight of them practicing at least part-time; three were serving as medical directors of palliative care programs; six were directly involved in a hospital-based palliative care program; five played a role in administering a palliative care program; six were engaged to a significant degree with hospice patients; five played leadership roles in palliative care affinity groups; five served as academics in palliative care; eight conducted research in the field; seven were widely published; most were involved to some degree in an affinity group either local, national, or both; three had been or were at the time of the interview involved in doing work for Medicare; and four of them were recognized repeatedly by those in both interview groups as being prominent leaders in the field of palliative care. They described the focus of their work as it relates to advancing the current “palliative care agenda” as shown in Table 27.
Table 27

*Focus of Palliative Care Expert Informants Organizations’ Work in (or Related to) Palliative Care (N = 12)*

<table>
<thead>
<tr>
<th>Focus on Team-based Issues</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>58</td>
<td>7</td>
</tr>
<tr>
<td>Collaboration efforts</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Training</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Quality improvement</td>
<td>42</td>
<td>5</td>
</tr>
<tr>
<td>Hospital-based palliative care</td>
<td>33</td>
<td>4</td>
</tr>
<tr>
<td>Advanced care planning</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>End-of-life care</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Development of leadership for the field</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Focus on team-based issues</td>
<td>17</td>
<td>2</td>
</tr>
</tbody>
</table>

*Specific Findings*

Through the use of the same interview guide with each of the informants, the researcher gathered data related to the overarching question, “What do palliative care experts perceive to be the current priorities, gaps, best strategies, best private funding opportunities, and best private funding strategies for the field of palliative care?”
Existing gaps.

The top two gaps listed by informants were lack of awareness and insufficient training. Close behind those two gaps were four gaps (listed in Table 28) that in combination with the first two, indicated dominant themes that were repeated throughout the interviews. They are: (a) general awareness of palliative care; (b) development of needed human resources in palliative care; (c) changes in prohibitive reimbursement structures; (d) increased and appropriate support for patients and families; (e) development of better pain and symptom management; and (f) availability of palliative care to all (including culturally competent care).
Table 28

*Palliative Care Expert Perceptions of Existing Gaps in Palliative Care*  \( (N = 12) \)

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of awareness/need to raise awareness</td>
<td>58</td>
<td>7</td>
</tr>
<tr>
<td>Insufficient training</td>
<td>58</td>
<td>7</td>
</tr>
<tr>
<td>Medicare/payers do not provide appropriate reimbursement</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Palliative care is not available enough/not part of overall care</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Not enough hospitals have programs/have staff that understand</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Medical system does not support palliative care</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Palliative care organizations do not have tools to be sustainable</td>
<td>42</td>
<td>5</td>
</tr>
<tr>
<td>Needs of families are not considered/taken care of sufficiently</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Private funders are not comfortable with issue/don’t fund it</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Leadership is not sufficiently developed</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Outpatient palliative care has not been developed</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Skilled nursing facility palliative care has not been developed</td>
<td>25</td>
<td>3</td>
</tr>
</tbody>
</table>

*Lack of awareness and the need to raise awareness.*

When asked about the main gaps that they perceived for the field of palliative care, informants talked a great deal about the lack of awareness that is experienced at all levels – patients, families, medical practitioners, healthcare executives and public officials. Informant J explained:
The public doesn’t have a clue what palliative care is. At a recent major meeting of academic palliative medicine leaders last November . . . one of the things we talked about was getting the words palliative care in the New York Times, but you don’t yet see it in AARP Magazine or Parade or Reader’s Digest. So, one of the things that I think is a critical need is to translate a message of what palliative care is in a way that the lay public can understand – something along the line of “Got Palliative Care?” When people go to the hospital they need to know how to ask for it by name and to have some idea of what they expect in return for that. That’s a real major gap right now. We’re just not getting that message across.

*Insufficient training.*

Training was also one of the most dominant themes that was discussed in the context of existing gaps and in other contexts. There was a sense in the field that a great deal had been done to raise levels of professionalism in palliative care and end-of-life care, in general. But, there was still a great sense that opportunities to provide appropriate care and operate more efficiently were being missed. In discussing the need for training, and the complexity of situations in which that need may arise, informant L said,

I think that on a couple of levels, if more doctors and nurses were really educated about hospice and palliative care, the referrals would get made a lot earlier . . . that’s the huge problem . . . because referrals don’t get made until the last week or two of someone’s life. If people weren’t afraid to say ‘OK I’m going to make a hospice referral, because I really do think within six months or so this person may well die.’ But, in order to even get to that place you have to dispel your own myths about ‘Oh my god, if I say the word
hospice, it means that they’re going to die tomorrow.’ It means that more people are going to be willing to at least open the conversation, like when someone’s in the hospital – or call in someone who can open that conversation. You know what happens so often is that I’ll get to the hospital to assess someone that is ready for hospice, and they’ve been in the hospital for weeks already. And a conversation that would have been way more helpful at the beginning of the hospital stay – understanding what the process was going to be, it is now something that we’re having in the last few days with the person more confused, in more pain, probably more agitated – and some of that is that the nurses who were there at the bedside eight hours aren’t empowered enough to be advocates.

*Medicare and payers do not provide appropriate reimbursement.*

Training, however, has been better implemented and received as a priority in all realms than has the need to change the way the reimbursement for care is administered. As mentioned in great detail in the literature review of this study, Medicare has long been recognized as one of the biggest problems for the delivery of palliative care. Respondent F, expressing the deep frustration that professionals feel at not being able to provide the care that they believe to be most appropriate said,

On the basis of data, which Medicare collected for a number of years, it was noted that hospitals are billing and making their margins on very high revenue procedures, mainly cardiac procedures . . . for which Medicare was paying way more dollars than it was costing the hospitals to provide these services. So Medicare came out and proposed reimbursing hospitals based more on what they actually do as opposed to what they charge for, which meant that there was gonna be cuts of a third or more in . . . the real
revenue producers that hospitals thrive on right now. Of course, the makers of the stents, devices, defibrulators, all the suppliers for those cardiac procedures and, of course, the hospitals themselves, all provided an advertising campaign and a very intense lobbying campaign that caused Medicare to pull back on that plan, which would have – and this is what is so maddening – which would have redistributed Medicare reimbursements so that the people who are really sick – the chronically ill patients – their services would have been better reimbursed so that they would get better care than they are now getting. They are getting shortchanged in favor of all these procedures, but that was rolled back by force of advertising and lobbying by these device makers, and hospitals . . . And the outcomes of these procedures don’t necessarily result in better health or longer life for large numbers of patients. On the other hand, the people who need the care – the elderly very sick patients, whose families are going bankrupt trying to care for that, are not gonna be reimbursed after all. I can’t believe that this didn’t make Sixty Minutes, but no one paid much attention at all.
Palliative care is not available/not part of overall care to a sufficient degree.

That Medicare and other payers have not developed systems for reimbursing for palliative care appropriately, was reinforced by Informant J, who explained that palliative care is still not seen as a medical essential:

Too often, in my view, palliative care is still seen as something that is nice, that hospitals are increasingly being asked to have – but the very fact that it is nice hospitals often see it as a luxury that they can’t afford – or can marginally afford. So an image that comes to my mind, is that we’re somewhat like Oliver Twist and coming up and saying, ‘Please sir, can I have a little bit more porridge.’ . . . There is clearly a gap in terms of the acceptance of palliative care in the field of healthcare.

Not enough hospitals have programs and/or staff that understand.

To those who work at the heart of the palliative care field there is a clear understanding about the fact that “Not all hospitals offer palliative care services, so lots of hospitalized patients don’t get palliative care services” (Informant D). They speak of their frustration at watching the suffering occur, knowing what needs to be done, and simply not having the ability to make the choices that they believe to be the right ones. They speak repeatedly about the lack of information and lack of training among their peers. It sometimes appears that even minimal amounts of training would lead to better informed professionals who would regularly see the need for certain kinds of palliative care services, and then would make referrals and create demand – and more importantly would get patients the kind of care that they need earlier.

Informant L remarked, “One of the major gaps is that early referrals are not made. By the time
they talk about it and admit someone who needs hospice or palliative care, it’s already so far down the line.”

*The medical system does not support palliative care.*

Awareness at every level, training, and reimbursement are concerns at the top of the priority list, but just as important is a much broader area: the entire medical system. It is recognized as large and complex, and yet it is often spoken of as if there are obvious weak points that could be addressed. Informant C explained in brief, “Every weakness in the healthcare system comes out in the dying process.” Informant F provided a deeper explanation that recognizes a bit more fully the complexity of the system at work, highlighting the evolution of a system that is not only not supportive of palliative care, but that is geared for patients of the last century:

What makes palliative care unfortunately so necessary are the gaps in the medical system overall . . . Our United States medical system is devoted primarily to disease-modifying care, provided in an acute setting according to pretty much an acute care model. . . . Our medical system is pretty ideally set up to handle the illnesses that we were seeing about a century ago, at the turn of the last century. At that point major causes of death were childbirth, trauma, acute infections . . . What makes palliative care necessary is that the patient population we’re now dealing with is nothing like the patient population last century. We’re now dealing with chronic debilitating illnesses that afflict people for a long time and running them to the E.R. with every exacerbation is neither appropriate nor cost effective. So palliative care is necessary to fill the tremendous gap that exists between the 98 percent of our system dollars that are devoted to acute curative care versus the 1 to 2 percent of our budget that is devoted strictly to care of the dying, which is called
hospice. There is a huge chasm that exists in the middle for elderly and very ill, but not yet dead – where medical needs, particularly at home, are completely neglected and unfunded. So that’s why palliative care pretty much has to exist, because the medical systems just hasn’t seen fit to provide for those people yet and shows no sign of beginning to do that.

Current efforts to close the gaps.

The informants who participated in the interviews also provided a great deal of detail concerning the efforts that were currently underway to close the gaps that they identified. Chief among these were efforts to develop the field of palliative care and make it a specialty in and of itself, along with rigorous training and collaboration across the United States. Table 29 relates the range of efforts that were discussed.
Table 29

Palliative Care Expert Perceptions of Current Efforts to Close the Gaps (N = 10)

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care is maturing as a field/becoming a specialty field</td>
<td>50</td>
<td>5</td>
</tr>
<tr>
<td>Rigorous training efforts/programs</td>
<td>50</td>
<td>5</td>
</tr>
<tr>
<td>Collaborative efforts and coalitions</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>Fundraising efforts under way</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>Dissemination of palliative care strategies, tools and models</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Public awareness campaigns</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Active hospice organizations/efforts to re-invent hospice</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Business/sustainability planning</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Research under way</td>
<td>20</td>
<td>2</td>
</tr>
</tbody>
</table>

Palliative care is maturing as a field and becoming a specialty field.

Many of the informants mentioned the fact the palliative care is becoming a subspecialty field in medicine. Most of the informants saw that as a positive sign that the medical system and society are recognizing a glaring need that has existed for some time. Informant J explained why this is so important: “That we are now becoming a subspecialty of medicine is a massive change. That we are part of process of being able to say what quality really looks like, to be boarded in palliative medicine you need x, y, and z.” Informant J explained that this all has to be tied to
rigorous training programs – in continuing medical education and the development of palliative care training programs within medical schools, and as fellowships and residencies.

*Efforts that have worked.*

In addition to the discussion of current efforts to fill the gaps, informants provided a great deal of detail on the things that have worked well in the field. Hospital-based palliative care, leadership development, palliative care training, research, and hospice were most frequently mentioned.
Table 30

Palliative Care Expert Perceptions of Efforts that Have Worked (N = 10)

<table>
<thead>
<tr>
<th>Approach</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital-based palliative care</td>
<td>100</td>
<td>10</td>
</tr>
<tr>
<td>Leadership development</td>
<td>70</td>
<td>7</td>
</tr>
<tr>
<td>Palliative care training</td>
<td>70</td>
<td>7</td>
</tr>
<tr>
<td>Research</td>
<td>70</td>
<td>7</td>
</tr>
<tr>
<td>Hospice</td>
<td>70</td>
<td>7</td>
</tr>
<tr>
<td>Spirituality</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>Collaborations/affinity groups/national organizations</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Raising awareness</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Creating culturally competent programs</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Development of out-patient services</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Development of palliative care in skilled nursing facilities</td>
<td>20</td>
<td>2</td>
</tr>
</tbody>
</table>

*Hospital-based palliative care.*

Explaining the humanizing side of palliative care that has been experienced in hospitals across the country, Informant G said, “People love being involved with palliative care because they see results, because the symptoms are well managed, because you see less suffering, because patients have time for closure, and we all get to witness that.” This theme was reiterated
by many of the informants, who explained their frustrations with current medical systems and trends, and then softened their tone as they explained the driving force they experience working in palliative care. They also enthusiastically described systems that work, and places where palliative care operates best. Informant F said of the Veterans Affairs system and its ability to function effectively and efficiently:

The VA has really put palliative care and connections with hospice near the top of its agenda because they really get it. They are a closed system that doesn’t have incentives at cross purposes. Their docs don’t sit there and bill for everything they do. They’re salaried so the VA really has their incentives aligned to try to prevent unnecessary hospitalizations.

*Leadership development.*

When asked what it will take to get the system to a place that is more like the one that informant F described, the development of strong leadership was cited almost without exception. However, it was also recognized that doctors, nurses, and other professionals are taxed to their limits. Because of this, unique palliative care recruiting and leadership development programs have emerged. Discussing the field and creative responses that have been developed, Informant E described one unique training program for doctors:

At one organization there is a wonderful way of getting doctors out that is Medicine and Music, which involves dinner where docs come with a guest . . . and then they have a social hour that is followed by a presentation or lecture and dinner. That is followed by everyone going to hear jazz music. . . . It is a big group activity that is very friendly, but when doctors are very pressed, very tired at the end of a long day, it’s amazing that they
will come out for this. I’ve heard people try all kinds of things to get doctors to come to meetings. . . . It’s a very tough sale because of doctors’ stress. This is one that seems to work.

_Hospice._

Hospice and its relationship to the emerging field of palliative care was mentioned consistently by informants throughout the interview process. While it was recognized that they continue to be important to one another for historical and practical reasons, certain aspects of hospice that the experts explained would be beneficial to palliative care continue to elude the field of palliative care. Informant L described one of the key components of the hospice model, which would ideally be more integrated into the palliative care models that are emerging “People in the hospice units are comforted because of the volunteer programs – the nurses and CNAs just don’t have time. They’re [volunteers] doing crossword puzzles with them, and taking them out in their wheelchairs, and finding out who they were during the rest of their lives.”

_Efforts that have not worked._

Informants talked a great deal about efforts that have not worked (see Table 31).
Table 31

Palliative Care Expert Perceptions of Efforts That Have Not Worked (N = 11)

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care training is still not sufficiently provided</td>
<td>45</td>
<td>5</td>
</tr>
<tr>
<td>Palliative care team approach is not widely enough used</td>
<td>45</td>
<td>5</td>
</tr>
<tr>
<td>Insufficient funding/payers and Medicare don’t reimburse</td>
<td>36</td>
<td>4</td>
</tr>
<tr>
<td>Private funding didn’t bring palliative care full scale/was pulled</td>
<td>18</td>
<td>2</td>
</tr>
<tr>
<td>Dissemination has been inadequate/those in charge burn out</td>
<td>18</td>
<td>2</td>
</tr>
</tbody>
</table>

Among the items that were spoken of with some frequency were insufficient palliative care training, insufficient use of the palliative care team approach, and insufficient reimbursement by payers, and Medicare in particular. These responses reinforced the dominant themes emerging from the palliative care expert interviews.

**Palliative care training is still not sufficiently provided.**

Informant L talked about learning firsthand just how limited palliative care training for medical professionals still is:

This past winter we had second-year medical interns . . . and a couple of weeks into it I asked, ‘So is this just part of a bigger course that you are doing in palliative care’? And they said, ‘Well, no, we have one other session and then three more hours in the field.’ And I thought, ‘Wow, I’ve got to say a lot of things in three hours.’ I mean, it was pretty shocking.
Palliative care team approach is not widely enough used.

Paired with the realization of how limited palliative care training is, was the observation repeatedly reported during interviews that, although widely proven to work, the palliative care team format is still not fully implemented. Informant G expressed the importance of the team and the frustration of dealing with those who have not been trained and do not understand its value:

A palliative care team addresses the need, puts the time in. The palliative care team serves as the liaison between the nursing staff, the physicians, the case manager, the social worker, the chaplain. . . . It works, it is really really effective. And, nurses and doctors [not trained in palliative care] can’t appreciate it; both have complete knowledge deficits.

Payers and medicare don’t reimburse sufficiently.

Informant F spoke about programs that fell apart because of the lack of appropriate reimbursement mechanisms and resources, and about trying to be innovative despite restrictive parameters:

Nurse practitioner-based programs fell apart because the reimbursement went away—under a capitated system where you are paid a member-per-month charge for every covered life in your system you can make something like this work, but we had to basically scrap that system because the nurse practitioner is too expensive. We had to adapt . . . into the home care environment where there is reimbursement. And, so I’d say to generalize, systems that don’t work are systems whose providers are either too costly—like nurse practitioners in certain settings, or where you’re short of staff because there’s a
nurse shortage everywhere – particularly in the Bay Area because the cost of living is so high that nurses often can’t afford to live there. You have to make sure that your interventions are staffed in such a way that . . . the cost of the salaries can be spread across a population where there is some reimbursement.

Informant F went on to explain that dealing with such reimbursement systems and trying to maneuver within them only goes so far, because they are not appropriately set up. This puts practitioners in the position of trying to serve patients, while being told by the business side of healthcare that it can’t be done:

I hate to sound like a broken record, but Medicare reimbursement is so skewed toward acute curative-device-procedure based care for patients who aren’t really ill yet, and so inadequate for patients that are old and sick, that it just doesn’t work for palliative care. I constantly have the chief financial officer breathing down my neck and telling me that my program may not survive because the reimbursement isn’t there.

_Private funding didn’t bring palliative care to full scale._

Many palliative care experts who participated in the interviews made mention of the extensive funding that occurred over the period of more than a decade, but explained that it has all but dried up. Informant J explained that there was a ‘sort of a seismic wave that hit us . . . [when] they pulled out. Frankly I think in terms of funding support we’re just now getting over our withdrawal from that addiction to those programs. It’s getting better, but there is a bit of a vacuum created there. . . .’ But informant J also felt that the palliative care experts understand that they need to take responsibility for their work going forward, and that they have. They are finding funds and making the work happen despite the changes in the private funding climate. ‘I
have to say, having lived through – I was funded and had to go through that process – I am impressed by the resiliency of the leadership I know.'

_Capacity for measuring impact._

Table 32

_Palliative Care Expert Perceptions of Capacity for Measuring Impact (N = 9)_

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Measurement in palliative care is difficult</td>
<td>78</td>
<td>7</td>
</tr>
<tr>
<td>Simple things can be measured</td>
<td>67</td>
<td>6</td>
</tr>
<tr>
<td>There is interest in development of measures</td>
<td>22</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 32 demonstrates in a very straightforward way the predominant messages conveyed by informants regarding measuring the impact of palliative care: It is difficult, simple things can be measured, and there is interest in developing it. While this is a reasonably hopeful sounding message, the table also demonstrates that 78 percent of those who made comments about measuring impact noted that it is very difficult to do, and that this is the predominant sentiment among the experts interviewed who are working in the field.

_Measurement in palliative care is difficult._

Informant F started on an upbeat note saying, "As far as the field goes, we have gotten better and better at beginning to discern what important outcomes are and how to measure how well we’re doing toward getting at those outcomes," but acknowledged, "There needs to be
major work done in terms of outcome measurement in palliative care.” This provides a general overarching idea, but Informant J explained with more detail the complexity – and in some ways the impossibility – of measuring the principle benefits of palliative care:

The biggest thing they are struggling with in trying sustainability is, ‘How do I demonstrate the value added I have to this healthcare organization in terms of economics?’ And the challenge in doing that is that most of the studies suggest that value added by palliative care programs is in cross-savings, – not in money earned, unlike the vast majority of other healthcare. . . . One of the biggest practical challenges in palliative care programs is proving the negative and that is incredibly difficult to do. A metaphor I might use. You can put someone on a blood thinner, they don’t get a heart attack, they don’t get a stroke. If you’re in a real hospital proving how many strokes you prevented in 50 patients is not only difficult, it’s impossible. You can’t prove it in those people. You need a research design, and yet many of the palliative care programs are being told to prove that they saved this money. So, many of the programs are struggling, some of them don’t even recognize that they are being asked to prove a negative, when no one knows how to do that. That’s a big challenge. It’s a radically differently challenge for the guy who puts in fancy surgical things. All he has to show is on the bottom line if he’s making more money than he’s spending. Proving outside of a research effort real cost savings is extraordinarily difficult and it’s a key question of survival for palliative care programs.
Simple things can be measured.

Several of the informants talked about the things that can be measured. Informant D said, "We can measure some symptoms. We can measure satisfaction. We can measure financial outcomes. But, we don’t have robust tools to really to do a lot more than that. There are subtleties that get lost if some of the measures are just kind of crude." But informant L puzzled over the question. "How do you measure whether somebody had a good death or not? I don’t know." He then considered measurement of the numbers of people who are actually taken care of, or that apply to be taken care of. "I mean, I turn away many. Between last January and April I had something like 65 or 70 needing hospice. Looking at the numbers of people who need it and are able to get it [is one way of measuring]."

How the field has changed.

When asked to offer thoughts on how the field has changed, the most often mentioned themes were that palliative care is now recognized as a medical specialty and that it is more available and integrated into healthcare. Table 33 reflects these dominant themes and several others revisited throughout the course of the interviews.
Table 33

Palliative Care Expert Perceptions of How the Field Has Changed (N = 9)

<table>
<thead>
<tr>
<th>Perceived Change</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care is recognized as a medical specialty</td>
<td>67</td>
<td>6</td>
</tr>
<tr>
<td>Palliative care is more available/more integrated into healthcare</td>
<td>67</td>
<td>6</td>
</tr>
<tr>
<td>Leaders have emerged/are committed to palliative care</td>
<td>33</td>
<td>3</td>
</tr>
<tr>
<td>More people know about it</td>
<td>33</td>
<td>3</td>
</tr>
</tbody>
</table>

Palliative care is recognized as a medical specialty.

Informants expressed a sense of accomplishment that so much has happened in such a short period of time, but also a tone of matter-of-factness that the logical things that need to occur have occurred. Informant J said:

I would date it to over roughly the last 10 years: A major change in the movement has been addressing the systematic problems. That includes having a seat at the table, by being a formal subspecialty of medicine, that includes going where the patients are, taking hospice concepts and putting them in acute care hospitals where most of the sick people receive their care.

Palliative care is more available/integrated into healthcare.

Informants repeatedly expressed a sense of real accomplishment and pride at having done what many of the informants believed to be remarkable. As informant A said, “Our ability to
Professionals who have worked in the field, and those who are new to it, repeatedly remarked on the success of palliative care emerging as a top choice and priority for future work. Informant F described an exercise that demonstrated this well:

We’ve had large meetings where all the cancer service line providers throughout my organization have been gathered together. We did the old group dynamics exercise where everybody comes up with all the things they could possibly want in cancer care and prioritizes and puts the colored dots on the one thing you like the best. Palliative care came out first or second on everybody’s list among all the cancer centers among all the leaders as to what was needed. Palliative care or research came out one and two.

Leaders have emerged and are committed to palliative care.

The palliative care experts who participated in the interviews discussed the leaders in the field, many of them by name. They spoke of those individuals in terms of their success and the challenges that lie ahead of them. Informant F described a top priority for the field: “Positioning palliative care as a discipline so that it can assume a leadership role in dealing with the patient population that we are now just beginning to see: aging and those with chronic illness.”

More people know about it.

In answer to the concern that one of the greatest gaps in palliative care is that not enough people know about it, Informant C noted that this has to do with people’s fears and inability to accept basic truths. Informant C also explained that the tide is turning to some extent: “A great weakness for our culture is that people are terrified of death and disease. They trigger a
primitive emotional fear — so thinking about it means being able to overcome the primitive fear. Some can and some can’t; increasing numbers can. It is no longer so unseemly to talk about it.”

A part of what the palliative care experts focused on in the interviews was the humanizing aspect of palliative care, and the need for concepts that help people shift their perspective. Informant E said, “One of the ideas that people seem to like is that people are very vulnerable at birth and they are very vulnerable at death and that we will not abandon people in these times of vulnerability. There is a lot of commitment that we will not abandon people that need help.”

Informant J offered some historical perspective on the acceptance, familiarity, and use of the term palliative care. “I followed the history of this quite carefully [at the organization I work for] and I’m pretty sure that prior to the year 2000, incredibly, the term palliative care simply didn’t exist — at least in our lexicon and in most others.” Informant J was astonished “that we have gone literally [at this organization] . . . from a time where the vast majority of people, clinicians and hospitals, couldn’t even say the term, and they had no idea what it was — to at least having heard of it, is a huge change.”

The palliative care agenda.

Through their interview participation the informants collectively laid out the agenda depicted in Table 34. Training, making palliative care more available, development of the specialty, development of standards, changes in reimbursement, raising awareness, and attention to the support that patients and families need, received top mention, again repeating predominant themes.
Table 34

*Palliative Care Expert Perceptions of the Palliative Care Agenda (N = 12)*

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training adequately</td>
<td>67</td>
<td>8</td>
</tr>
<tr>
<td>Making palliative care available/part of overall healthcare</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Development of palliative care as a medical specialty</td>
<td>42</td>
<td>5</td>
</tr>
<tr>
<td>Insuring quality care/instituting standards</td>
<td>42</td>
<td>5</td>
</tr>
<tr>
<td>Changes in Medicare/palliative care financing/reimbursement</td>
<td>33</td>
<td>4</td>
</tr>
<tr>
<td>Raising awareness/family education</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Raising levels of culturally competent care</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Further development of existing programs</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Promotion/dissemination of team-based approach</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Further development of hospital-based approach</td>
<td>17</td>
<td>2</td>
</tr>
</tbody>
</table>

Training adequately.

Informant D highlighted the need for professional education that goes beyond the standard continuing medical education approach and shows how to make it cost efficient:

I would put emphasis on professional education . . . more than just sitting through 12 hours of lecture, but really trying to give people real training with meat on it. What we’re doing now is better than nothing . . . and perfectly good, but we know how to do a much better job than that. It isn’t always economically feasible, so figuring out how to do it in
an economically viable way – if not, at least getting some support to make it possible, so we can increase the number of people who can provide this kind of care. A number of the informants focused on shifts in philosophy related to the education that is necessary at this point. For example, informant K explained:

If I was managing palliative care training, one of the key things that I would teach would be how to be effective agents of change, because the one thing we know is that you don’t want to grow old in the system that you’ve got. They have to learn how to manage change. How do you monitor it? How do you motivate people?

Making palliative care available and a part of overall healthcare.

Informant F expressed the frustration over knowing what needs to be done, and knowing that the capacity exists, but that everyone doesn’t have access to what they need at the time that they need, and that there is a great deal of suffering. “Patients and families out there are miserable with mom and dad in pain all day and all night, and everybody knows that we need to do better.”

Development of palliative care as a medical specialty.

Noting that there has been a trend to get a palliative care team in place, whatever the cost, and whatever the quality of care, Informant J said, “Certainly there is a risk . . . that the important thing is to get a palliative team, it doesn’t matter if it is of any quality or sustainable. Many, many programs are saying right now, ‘Gee we get it, to get on the list in U. S. News and World Report or for whatever reason we need to be able to say that we have a palliative care program’.”
Informant J went on to explain that when palliative care programs first began, it was most important to get them started, even if they didn’t have defined standards or parameters:

I’m not sure that that was a mistake in very early days, but I think it’s a critical challenge for the field right now to start answering those questions about what are really ideal ratios of clinicians of different types and how do you make the program sustainable and be able to say with some assurance, we have a quality product. I think if you look at other fields, over time they have been able to do it . . . If you don’t have that minimum, which means credentialing and people with certain competencies, you just don’t have it. Right now that is one of the biggest challenges for palliative care, is to create a product that people can say, ‘This is what a quality program looks like, and this other thing over here – whatever it is – that doesn’t look like a quality palliative care program’.

Changes in reimbursement.

Informant F stated very strongly that, “Priority number one is change Medicare funding.” Others also expressed this opinion, although not as adamantly.

Regional grantmaking.

Informants were asked to provide thoughts on best opportunities for regional grantmaking. Among their top recommendations were raising awareness, creating consumer demand and supplying it, supporting collaboration, and training palliative care professionals. Once again, most of the recurring themes emerged. However, the responses to this question in the interview, elicited a category that the researcher called, “Fund strategically for lasting change/appropriate-sized funding.” Informants appeared to have strong opinions related to the
work of funders who they had witnessed over the last decade. These responses are presented in Table 35.

Table 35

<table>
<thead>
<tr>
<th>Palliative Care Expert Perceptions of Best Opportunities for Regional Grantmaking</th>
</tr>
</thead>
<tbody>
<tr>
<td>(N = 12)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raise awareness (patient/caregiver/public/leader/medicine)</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Create consumer demand and supply it</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support collaboration/affinity groups</td>
<td>33</td>
<td>4</td>
</tr>
<tr>
<td>Train palliative care professionals</td>
<td>33</td>
<td>4</td>
</tr>
<tr>
<td>Fund strategically for lasting change/appropriate sized funding</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Develop out-patient services</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Use community advisory boards/palliative care expertise</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Continue support for existing palliative care programs</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Change the Medicare benefit through demonstration/advocacy</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Increase palliative care program self-sufficiency/sustainability</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Support bridges to hospice/greater use of hospice</td>
<td>17</td>
<td>2</td>
</tr>
</tbody>
</table>

*Raise awareness.*

Raising awareness continued to emerge as a top recommendation. The fact that patients and their families do not know the term palliative care or what it involves is seen as a top
problem to be addressed. Informant J reinforced this idea and spoke to concepts of informing the public to create demand, to obtain a place in the medical care market for palliative care:

Very rarely when I do a palliative care consult do I find a patient who knows what I am. When I say ‘Hi I’m from palliative care,’ they say, ‘What the heck is that?’ They don’t do that with a cardiologist or an oncologist. That’s not a trivial issue. If they don’t know what it is, how are they going to know that there’s any competition in terms of where they go? . . . There is no incentive from a marketing perspective for those programs to develop it because we aren’t competing on it.

Create consumer demand and supply it.

Informant J continued in relationship to the concept of creating consumer demand and supplying it, discussing the market and explaining, “If you went up to someone who is seriously ill and ask them if their healthcare organization had palliative care available to them – nobody knows what it is.” Informant J further explained that there is need ‘to get slogans out there like ‘Got Palliative Care?’ and making the public aware of board certification.’

Informant L reinforced this concept:

Education for patients and families, because if they don’t understand what palliative care means and what its about and what the resources are available to them, then they’re not going to ask for it. And part of what happens with medical care in this country is that, it still is consumer driven, and when enough people say I want this and I need this, then doctors have to get on board. And so, that’s what I think. . . . Education on every level: about what pain management means, about what good pain management means. What good end-of-life care is about.
Support collaboration and affinity groups.

Informant K emphasized the need for collaborative groups to provide insight and direction. “There are no existing mechanisms to make city or regional decisions about palliative care in San Francisco and therefore you are blocked on making decisions on what matters. No one party, no single hospital, for example, can manage the reforms that are needed. The system is only as good as its weakest link. When you have many weak links you are going to have lots and lots of errors.”

Fund strategically for lasting change.

Informant I laid out a complete plan for the funding:

There are three ways to think about it: One: Programmatic funding can help programs get launched, can help an institution get launched by linking that organization with resources for implementing palliative care and connecting them with palliative care centers. Not reinventing the wheel. …Two: Education for current trainee students and having curricular innovations for students and residents to get them the training. The other aspect of that is for people who want to make a mid-career change – say physicians or nurses who are practicing and want to make a career change to do palliative care. This is very difficult for somebody who has been practicing. It is often financially not viable, supporting mid-career retooling. Three: Support the generation of new knowledge through research.

Informant D spoke of specific needs in the Bay Area:
In the Bay Area beds are so limited... even though most people want to die at home, there is this group of people that don’t want to die at home, or who can’t be cared for at home and the hospital isn’t right and the nursing home isn’t right – and an in-patient hospice would be just right. But, those beds are really quite limited.

*Develop out-patient services.*

One of the topics that was not discussed frequently by the informants, but that did make the list, was the theme of the development of out-patient services, which along with the development of palliative care for skilled nursing facilities, is perceived as one of the new frontiers for palliative care development. Informant D explained, “There are very few outpatient services other than hospice. It is very hard for patients, who are not hospitalized to access palliative care services other than hospice.”

*Change medicare benefits through demonstration projects/advocacy.*

Although it did not rate at the top of the list, changing the Medicare benefit is an accepted “must-do” in order for deep and lasting change to be made. Informant F advised funders:

If I were a funder I’d be looking very hard for something that works for a Medicare project so that Medicare could find an excuse to provide this kind of reimbursement. Otherwise you’re going to have people like us drying up and going away because there is not enough reimbursement to keep us alive in the face of folks who want to cut costs and are looking to cut us.

In relationship to this comment, and demonstrating the difficulty of changing policies, informant K said, “There are three main reasons for slow movement in policy change: One,
optimal care for the last phase of life usually is not a good source for provider income. Two, those making a living with current practices resist change. Three, advocacy for better end-of-life care has thin agendas and thin backing."

_Increase palliative care program self-sufficiency and sustainability._

Accepting the thought that Medicare may not be likely to change quickly relative to the development of palliative care, many of the informants explained that it is important to continue to find routes for working within the existing parameters and for developing sustainability despite the challenges of reimbursement. Informant J lamented that a successful palliative care program had been cancelled because it was seen as an extra program, rather than as an essential one: “There is a hospital in the South Bay that had a palliative care program and within the next month or so it will be defunct. Those people are out looking for jobs. That is not an unlikely scenario.”

_Support bridges to hospice and greater use of hospice._

Another concept that was mentioned less frequently, but considered to be quite important, is having “a bridge between home health and hospice” (Informant L). Informant L explained that this “is a good model for the future, if that bridge – what we’re really trying to do – is truly understood by the practitioners.” Informant L emphasized the need to continue to keep hospice as one of the central resources for palliative care programs and for home health programs, and to continue to get patients into hospice at appropriate times, so that their care is maximized and so that hospice can do what it does best.
Large-scale regional grantmaking.

Informants made limited comments when asked what they would do if they were charged with large-scale regional grantmaking. Most said they would do the same things that they had already mentioned, but some emphasized raising awareness and training professionals, indicating that they considered those two things to be the most costly.

Table 36

Palliative Care Expert Perceptions of Best Opportunities for Large-Scale Regional Grantmaking (N = 10)

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same priorities already mentioned</td>
<td>90</td>
<td>9</td>
</tr>
<tr>
<td>Raise awareness (leaders/medical profession/public/patients)</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>Train palliative care professionals</td>
<td>30</td>
<td>3</td>
</tr>
</tbody>
</table>

If money were no object at informant organizations.

Informants were also asked what they would do if money were not a constraint at their organization. Research emerged as the top item, and training was second.
Table 37

If Money Were No Object at Palliative Care Expert Informants’ Organizations \( (N = 10) \)

<table>
<thead>
<tr>
<th>Priority</th>
<th>Percent</th>
<th>( n )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>80</td>
<td>8</td>
</tr>
<tr>
<td>Training</td>
<td>50</td>
<td>5</td>
</tr>
<tr>
<td>Same priorities already mentioned</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Quality improvement</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Make palliative care more available/part of overall healthcare</td>
<td>20</td>
<td>2</td>
</tr>
</tbody>
</table>

*If money were no object at informants’ organizations*

Informant L said, “The priorities would be the same in terms of education on all levels,” and added a thought about the importance – and heavy cost – of providing “the physical places, residential facilities, and residential hospices where people can really be taken care of and where ongoing support for loved ones can also be provided.”

*Informant Visions for Palliative Care*

Each of the informants was asked to describe their vision for palliative care. Most spoke about making palliative care available to all people, and throughout the continuum of healthcare. Forty percent expresses a vision that included increased spirituality being a key part of what needs to occur. Beyond that there was a great variety of things that were mentioned in what were fairly succinct statements. Table 38 describes the dominant themes.
Table 38

*Palliative Care Expert Visions for Palliative Care (N = 11)*

<table>
<thead>
<tr>
<th>Vision</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care would be available to all, throughout healthcare</td>
<td>82</td>
<td>9</td>
</tr>
<tr>
<td>Society will better address spirituality issues</td>
<td>45</td>
<td>5</td>
</tr>
<tr>
<td>Medical professionals will have better communication skills</td>
<td>18</td>
<td>2</td>
</tr>
<tr>
<td>Individuals will plan in advance (advanced directives, etc.)</td>
<td>18</td>
<td>2</td>
</tr>
<tr>
<td>Society's systems will better address end of life/chronic disease</td>
<td>18</td>
<td>2</td>
</tr>
</tbody>
</table>

**Palliative care would be available to all, throughout healthcare.**

Informant D represented much of what was said by many of the informants:

My vision is that patients can get palliative care wherever they are at any stage of their illness. They can get it when they come to any hospital. They can get palliative care in the outpatient setting. They can get it at home. They can get it alongside any other treatment they’re getting. And part of that is that their doctors and nurses will have a basic knowledge of palliative care to provide them with basic symptom management, the basics of communication. That will be available from all doctors and nurses, and they will be expert referral sources for people who need more than that. And, that you could really get it anywhere that you were, at any point in your illness.

Informant E said, “Palliative care will become part of the continuity of care, so that as people go through with their medical history, their life course, there are episodes of acute illness,
possibly hospitalization, and accidents. At some point there is likely to be chronic disease that
will go through various stages. Palliative care needs to be available at the end-of-life, though
pain relief should be available at any time in life. It should be available very seamlessly.”

Informant G spoke to the need for earlier palliative treatment in terminal care. “So few
patients get into hospice for such a short length of stay. We are missing the majority of
patients.” Also speaking to the importance of hospice and its origins being at the heart of needed
change and development, Informant L said:

In the old old days when hospice was the place where weary travelers pull off the road of
their pilgrimage, it was different. Hospitals aren’t a place where people go to have a
quiet and peaceful death. So, the idea of de-medicalizing death and having houses where
people can be and be comfortable and be cared for. I would love to see the idea of every
neighborhood having a hospice house.

Informant J expressed the desire to have palliative care be the norm, and be seen as an
essential and accepted part of healthcare:

To put the most optimistic spin on it, I would that one day palliative care is considered to be
nothing special. And what I mean by that, is that people could not imagine that one could
practice healthcare without palliative care. Again, by analogy, at least in modern healthcare,
a hospital simply could not imagine functioning without . . . nurses.

_Society will better address spirituality issues._

Informant L related being asked by a medical student what made doctors who are good at
dealing with palliative care-related issues and connecting with their patients on a human level.
Informant L said, “People who have done their own personal work, who have looked at these
issues in their own lives, who have been willing to go to some deeper emotional places in
themselves and translate it into who they are as a doctor or as a nurse. When you’ve never really
looked at some of the deeper questions, how can you really be there for somebody else who is
going through this?” While most of the informants did not go into this much detail about
spirituality, they were concerned with the human connections between medical professionals and
patients.

*Medical professionals will have better communications skills.*

In an effort to describe the need for better communication and deeper understanding of
the patient and family experience on the part of the physician, Informant F reflected on the fact
that most conversations related to palliative care occur on the “operations and financing level.”
Informant F then explained:

My vision for palliative care is to see a discipline, or a community, or network of
providers across settings where we can really link hospice and the rest of the medical
system together and create a real continuum of care, particularly for elderly patients with
advanced illness. But, I would also put in there that I think that we’ve paid a price.
Everything that we’ve talked about so far has been on the operations level, the financing
level, or the outcome-measurement level. All those things are well and good, but what
often gets left out – or what *usually* get’s left out – on those levels are the intangibles,
like the spiritual aspects of the struggles that patients and families go through for
meaning near the end-of-life and the despair that a lot of patients and families go through
when they get seriously ill and when one of them is dying and there is nobody around
who is willing to speak, or even able to speak to people about what they are actually
going through in their hearts. My vision would be that we develop a vibrant, robust, strong language for dealing with suffering and despair toward the end of life. You know, we just slap a label of depression on it and try to measure it and throw drugs. And that’s not what it’s about, it’s about finding ways to deal with spiritual suffering and to provide better and better support to – just the healing power of presence – to really begin to study and look at what it means to be present sitting face to face with somebody who is suffering and being able to provide the quality of presence that allows people to know that they’re not alone in their torment, they are not abandoned. We’re terrible at that. Even in palliative care we have a lot to learn, but particularly in medicine as a whole, we abandon patients and families all day every day – and especially all night every night. It’s the dark night of the soul for most patients who are sick and dying and we don’t even have a language to express where the needs are there; so we need to develop that more fully.

*Individuals will plan in advance.*

Mention was also made of the movement toward advanced directives, and planning end-of-life care in general. Informant H noted that patients and their families need to be empowered, “to be a part of that decision-making process for when it happens to them.”

*Society’s systems will better address end-of-life and chronic disease.*

Some of what informants explained was that palliative care is an answer to some very basic needs, an answer to society’s inability to address the needs of those with chronic disease and those who are facing the end of life. Informant K said, “I see palliative care as a stepping
You develop palliative care because you’ve got really sick people that are going to get worse and then they’re going to die.”

**Interview Group Two: Palliative Care Funders**

**Rate of Response**

Seventeen funders who have conducted grantmaking in the fields of palliative care, hospice, end-of-life, or a closely related area were identified as potential informants for this interview group during the literature review process or through professional experience of the researcher during his tenure as a foundation program officer. Twelve of the 17 agreed to participate during the period in which interviews were administered (August 2006), providing a valid response rate of 70.6 percent. These informants were the subjects for the Interview Group Two section of the study (N=12).

**Description of the Characteristics of the Population Studied**

With the exception of one corporate foundation officer, the informants represented organizations that all had current assets value and total giving amounts listed on the Foundation Center’s website (www.foundationcenter.org). The types of foundations represented can be described as follow: seven independent foundations, three public charities, one community foundation, and one corporate foundation. They ranged in asset value from $9.4 billion to $106.6 million, and reported total giving between $369.5 million and $2.9 million. All of them had a major or partial grantmaking focus in healthcare, and the majority of them currently conducted some level of work in palliative care or a closely related field. The informants had the
following titles: five senior program officers, three program directors, two program officers, one vice president of programs, and one foundation president. The range of foundation type, asset value, total giving, grantmaking focus, and the range of grantmaking program positions represented by the informants provided a variety of perspectives on strategic grantmaking in healthcare, palliative care, and fields related to palliative care. The respondents described the focus of their grantmaking work as it related to advancing the current “palliative care agenda” in terms presented in Table 39.

Table 39

<table>
<thead>
<tr>
<th>Focus of Palliative Care Funder Informants’ Organizations’ Palliative Care Work</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Raising awareness</td>
<td>42</td>
<td>5</td>
</tr>
<tr>
<td>Skilled nursing facilities</td>
<td>33</td>
<td>4</td>
</tr>
<tr>
<td>Availability and continuity of palliative care</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Collaboration efforts</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Hospital-based palliative care</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Quality issues</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Research</td>
<td>17</td>
<td>2</td>
</tr>
</tbody>
</table>
Specific Findings

Through the use of the same interview guide (See Appendix E) with each of the informants, the researcher gathered data related to the overarching question, "What do healthcare funders currently working (or who have previously worked) in the field of palliative care grantmaking perceive to be the current priorities, gaps, best strategies, best private funding opportunities, and best private funding strategies for the field of palliative care?"

Existing Gaps

The top three existing gaps cited by the informants for Interview Group Two were lack of awareness, insufficient reimbursement and insufficient training, which are the same three factors that were noted by the palliative care experts in Interview Group One.
Table 40

_Palliative Care Funder Perceptions of Existing Gaps (N = 12)_

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of awareness/need to raise awareness</td>
<td>58</td>
<td>7</td>
</tr>
<tr>
<td>Medicare/payers do not provide appropriate reimbursement</td>
<td>42</td>
<td>5</td>
</tr>
<tr>
<td>Insufficient training</td>
<td>42</td>
<td>5</td>
</tr>
<tr>
<td>Cultural competency issues are not fully enough addressed</td>
<td>33</td>
<td>4</td>
</tr>
<tr>
<td>Family needs are not considered/taken care of sufficiently</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Leadership is not sufficiently developed</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Pain management is insufficient</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Palliative care is not available enough/not part of overall care</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Advanced care planning is not sufficiently in place</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Emotional support not adequately provided to patient/caregiver</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Hospice is not used sufficiently/is limited by Medicare</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Hospital-based palliative care is not widely enough available</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Private funders are not adequately involved/insufficient funding</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Research levels are insufficient</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Skilled nursing facility palliative care has not been developed</td>
<td>17</td>
<td>2</td>
</tr>
</tbody>
</table>
Lack of awareness.

Funders expressed their opinions about the lack of awareness of palliative care, many of them citing the need for patients and their families to experience less suffering and more comfort through chronic disease and at the end of life. Informant II explained, “understanding that there is a need ... that palliative care provides dignity to patients at the end of their lives rather than intrusive kinds of medical interventions that may do nothing to prolong life or that prolong it with added cost of care and comfort to the patients.” Funders also noted that as the palliative care movement matures it is reaching out to groups that have not been reached before by palliative care or by hospice. Informant BB said, “There are big gaps across the country as far as even awareness of hospice and palliative care, and I think there should be more money particularly in the rural areas to establish some way of providing care—hospice care, palliative care, for those that live in communities that cannot be reached by the larger organizations.” Informant JJ explained “trying to fund some of the things that those change leaders are trying to do,” is difficult because “people don’t understand palliative care and that there’s a difference between palliative care and hospice.” This latter point was remarked often throughout this study, that palliative care has grown out of the hospice tradition, but is really a field unto itself.

Medicare/payers do not provide appropriate reimbursement.

The perspectives of funders who have worked in palliative care expressed a number of fairly consistent themes. The top two are an understanding of the difference between palliative care and hospice, and the relationships between Medicare, other payers, and reimbursement. Informant CC described the difficulty experienced by families who have children that are in need of palliative care:
Very few children get hospice service because the doctor has to declare them within six months of death and they’ll start to forgo all forms of acute care—and that’s just something that most parents of kids and most pediatricians just won’t go along with. So, we’re trying to work with the state and with some other states on the Medicaid benefit, because we think Medicaid benefit needs to be expanded to begin to offer palliative care earlier on to families of kids that really are clearly critically ill.

Informant AA explained another of the classic reasons why the Medicare benefit needs to be altered:

The historic pattern is that most people die in hospitals. A lot of people want to die at home, but that’s not where they die. . . . Reimbursement makes it difficult for hospices. There is a lack of supportive policies. There’s not enough education or enough information so that policy makers have knowledge on which to base decisions. A lot of people in the field are not well-positioned or well-trained to make the arguments that need to be made.

Informants also noted the need for the addition of reimbursement for services that have not traditionally been a part of the Medicare reimbursement, that are not generally considered to be the most pressing concerns, but that do impact the lives of patients and caregivers. Some of the informants spoke specifically of caregivers and their emotional needs. Informant BB noted, “Bereavement is not part of the reimbursement system. As far as Medicare is concerned, it was never written into it. Often what’s not funded is just not done.”
Training is insufficient

Informant FF noted the extraordinary dearth of medical professionals trained to deliver palliative care, and emphasized that this will only get worse:

There are a lot more people in need of palliative care services and approaches and intervention than there will ever be people trained in palliative care. I think a major problem in the service delivery is to think that one has to be a specialist in order to do it. And, so how do you kind of drive an awareness of service – what the skills are – and give the skills and manage let’s say 90 percent of palliative care needs into the hands of existing professionals? I think that’s the big gap.

Although informants represented institutions from around the country, many of them were careful to note striking facts about California and the Bay Area. Informant DD noted, “There is a huge shortage of nurses in California. Only 517 have been trained through the ELNEC program (End-of-Life Nursing Education Consortium).” While this number is striking compared to the numbers from the broader field, which previously had no such training, it is still extremely low.

Cultural competence issues are not fully enough addressed.

Concerns about cultural competence issues were prominent throughout the interviews, and it was noted that palliative care programs and hospices “need to reach out more to the African-American community and the Hispanic community than they are actually doing” (Informant BB). Informant HH noted that the LGBT [Lesbian Gay Bisexual Transgender] populations “are hidden away and they might have a partner who needs palliative care” but is unable to access it for legal reasons or due to cultural barriers. Funders also have recognized that
“understanding their preferences and having programs and services that really respond to their specific needs” (Informant CC) is essential.

*Family needs are not considered or taken care of sufficiently.*

Concern for the needs of family, especially related to children, was mentioned repeatedly, in particular “the gap around children getting palliative care services and when we say palliative care we mean not necessarily foregoing the acute, but really beginning to deal with the sort of suffering and mental and spiritual issues that families need to deal with” (Informant CC).

Informant II also noted recent information about this in the media:

> There was a great NPR program on that the other day. . . . It was really helpful because it was a parent saying ‘Thank God that I finally am able to say, enough. My child doesn’t need this, doesn’t want this. Let’s make him comfortable.’ I think it’s empowering the patients, and the parents, and the spouses to make those statements to the medical community.

*Leadership is insufficiently developed.*

Several of the informants who participated in Interview Group Two recognized the significant number of leaders who have emerged over the last decade, but also spoke of the continuing need for leadership development. Informant DD recognized the need for palliative care leadership training. “Getting the new generation of doctors into fellowship programs where they become leaders [is important, and one way to do this is to] work in academic centers or others places, but create a cadre of leaders. That critical mass is important and we need to continue to develop it.”
Pain management is insufficient.

Funder informants demonstrated a strong interest in pain management issues, recognized that the area of pain management is grossly underdeveloped, and that “there are people who need pain meds, who can’t get them because of stereotypes and assumptions about how much pain they are really feeling, without really having a pain expert get involved. Pain management is a huge area as well” (Informant CC).

Palliative care is not available enough/not a sufficient part of overall care.

“Over 400 hospitals in California and only about 23 percent have any kind of palliative care program and . . . we don’t even know what that entails. Is that one doctor, or a consult team, is it an in-patient unit? We need real good descriptive data,” Informant DD said. Informant CC further described recent information about California hospitals:

Only one or two hospitals have any palliative care beds, and the rest of that percentage don’t even have palliative care services where you could call somebody in or where you have somebody doing in-service and really helping people understand. So there’s definitely a gap in hospitals where . . . there’s really that very strong medical tradition that you do everything you can to keep people alive . . . and I think that the concept of a good death is not something that people are really aware of. In terms of hospitals that’s a huge gap.

Informant EE reported that even the hospitals that are known for strong palliative care programs are failing to provide palliative care where it is need: “I still hear that patients have entered a hospital that is renowned for palliative care, and I am shocked that no one has talked with them about palliative care – not even a palliative care consult.”
But it is not only hospitals, as informant CC explained. “There’s definitely a big gap around nursing homes.” More and more, those who are marginalized are being considered. Informant HH explained, “We need to look at the whole state [of California] and not just the urban areas. One of the challenges is delivering healthcare services to seniors who are living in rural, isolated areas, where travel is a major impediment.”

Informant CC said, “There’s a huge gap in advanced directives. I think only one third of the population of California has anything in writing at all. The whole idea of people stating their preferences and that happening consistently, and communicating it with their providers and the providers asking and listening – that’s a huge gap.”

Emotional support is not adequately provided to patients and caregivers.

“If we’re talking about palliative care, which is providing pain relief – palliating symptoms, essentially the palliative care movement . . . the biggest gap that they have is providing more emotional support for patients and families” noted Informant BB. “I think that the biggest gap as far as hospice is concerned is that they have very little time with the patient and the family to provide that kind of emotional support or help.”

Current efforts to close the gaps.

Table 41 describes informant perceptions of efforts to close gaps in providing palliative care. Informants cited funding and fundraising as the top concerns, followed by collaborative efforts and training efforts.
Table 41

Palliative Care Funder Perceptions of Current Efforts to Close the Gaps (N = 12)

<table>
<thead>
<tr>
<th>Effort</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding and fundraising efforts under way</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Collaborative efforts and coalitions</td>
<td>42</td>
<td>5</td>
</tr>
<tr>
<td>Training efforts/programs</td>
<td>42</td>
<td>5</td>
</tr>
<tr>
<td>Raising awareness</td>
<td>33</td>
<td>4</td>
</tr>
<tr>
<td>Palliative care is maturing as a field/becoming a specialty field</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Advanced planning for end-of-life care</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Making palliative care more available</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Research under way</td>
<td>17</td>
<td>2</td>
</tr>
</tbody>
</table>

Funding and fundraising efforts are underway.

Informant AA discussed improvement in the field of palliative care funding, noting that a new foundation “has moved into palliative care and end-of-life issues. They did something like $6 million last year, and I believe that they will do [a significant amount] each year going forward.” Informant CC commented on a strategic approach to the funding situation:

Our board just approved a new set of goals and objectives . . . [focused on] improving the care that people get and . . . trying to avoid unnecessary care that they wouldn’t even want if they understood that they had a choice. There’s a feeling that there’s a lot of money spent at the end-of-life on care that is neither appropriate nor would people want it
if they really understood the situation. And we’re trying to both reduce costs in the healthcare system so that it is more affordable for everybody, and meet people’s preferences and get people quality care.

**Collaborative efforts and coalitions.**

Many of the informants mentioned having supported collaborations, affinity groups or coalitions. Informant JJ explained:

We’re looking at having a locus of responsibility for the whole topic of palliative and end-of-life care [in our state] so people will know where to go, how to get information, what should or what would work for them. We’re focusing on a palliative care partnership, trying to be the locus of responsibility and make sure that all the different programs and leaders that we have in the state are talking to each other and leveraging resources, and that duplication isn’t happening. So we’re very proud of that.

**Training efforts and programs.**

Informants talked about looking for ways to impact the medical system so that palliative care is more available. Informant II described recent funding provided to a hospice for a professional training program for “all primary care physicians in their residency training programs in every hospital in the county.” Informant JJ discussed targeting programs for:

... professionals in the field, in the faith communities, in the healthcare communities that are not in the position [to receive training generally]: the homecare agencies, the nursing home facilities, all the people around the edges that pass into palliative and end-of-life care. And we’re also focusing, particularly, on training the newbies, if you will – the new
doctors or nurses that are coming into the field. And, if we can change the attitudes and
culture before they get into the system, we feel we can have a better impact affecting the
larger system, if they come in with fresh eyes and a new attitude.

Palliative care is becoming a subspecialty field.

While there was quite a bit of agreement in the topics informants discussed, there were
some outlier comments. For example, Informant FF said:

I wouldn’t run out and train a couple thousand palliative care physicians and I wouldn’t
do a lot about creating a specialty for it. I really think that that’s the wrong way to go –
not that there isn’t a significant body of work and expertise that is surrounding it. But, if
you make it solely the problem of people who have been accredited or in some way
certified as being able to provide palliative care, I think it gets everyone off the hook of
having to deal with it.

Advanced planning for end-of-life care.

Informants described taking more strategic approaches to advanced planning, including
training programs for living will and personal care directives. Informant II described providing
support “in helping the secretary of state develop a registrar of living wills and personal care
directives online” and funding for “the attorney general’s office to develop a video that will be
used in training on the need for documents that describe a person’s wishes at the end of life.”
Making palliative care more available.

Informants described looking for creative new ways to invest, and where achieving impact had been thought to be very difficult. Informant CC said:

We’ve heard from a number of geriatricians that when hospice comes in and it’s really good hospice and they have a strong presence in a nursing home, it improves the care for everybody in that nursing home, not just the palliative care patients because they’ll have experts who really understand better how to deal with pain and other issues of suffering that people may be experiencing.

Research is underway.

Research has been conducted for years in the fields of palliative care and hospice, and in some cases such studies are becoming a part of the fabric of institutions, supported by funders. Informant BB discussed such research that is being conducted within specific institutions for quality improvement purposes that could benefit the field in general: “Many of the larger hospice organization have created departments to do a lot of research . . . and into how the work that’s being done in the community actually impacts the community. For example, the largest hospice in the U.S. has an entire department that does that kind of research.” However, informant BB further commented that it is often “just very difficult to get the type of information from terminally ill patients that would really be helpful, but I think that most – of especially the larger hospices and hospice organizations – are doing surveys to measure the impact in the community.”
Efforts that have not worked.

Table 42 describes efforts that informants claimed have not worked. Funder informants described insufficient funding and reimbursement, and lack of availability of palliative care as the top two efforts that have not worked. They also indicated that advanced planning programs have not reached enough people and that private funding often has not finished what it started in palliative care. This last item is especially striking, as funder informants were especially concerned and forthcoming about the action or inaction of their peer group.
Table 42

Palliative Care Funder Perceptions of Efforts that Have Not Worked \((N = 11)\)

<table>
<thead>
<tr>
<th>Effort</th>
<th>Percent</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insufficient funding; payers, and Medicare don’t reimburse</td>
<td>36</td>
<td>4</td>
</tr>
<tr>
<td>Palliative care is not available enough/not part of overall care</td>
<td>36</td>
<td>4</td>
</tr>
<tr>
<td>Advanced planning programs have not reached enough people</td>
<td>27</td>
<td>3</td>
</tr>
<tr>
<td>Private funding didn’t bring palliative care full-scale or was pulled</td>
<td>27</td>
<td>3</td>
</tr>
<tr>
<td>Cultural competence issues insufficiently addressed</td>
<td>18</td>
<td>2</td>
</tr>
<tr>
<td>Dissemination still not sufficient</td>
<td>18</td>
<td>2</td>
</tr>
<tr>
<td>Insufficient awareness and name recognition of palliative care</td>
<td>18</td>
<td>2</td>
</tr>
<tr>
<td>Palliative care training still insufficient</td>
<td>18</td>
<td>2</td>
</tr>
<tr>
<td>Research and development still not sufficient</td>
<td>18</td>
<td>2</td>
</tr>
</tbody>
</table>

Insufficient funding – payers and medicare don’t reimburse.

“The Medicare hospice benefit just doesn’t work, even though Medicare will pay for many things. They still don’t get it,” explained Informant CC, expressing what informants across the board and professionals throughout the field of palliative care understand. “If you look at a Medicare Advantage plan,” continued informant CC, “approximately $2 billion are wasted on care in the last 100 days of life that didn’t really do much. If you could get people into hospice a month earlier you could save a huge amount of money.”
Informant JJ explained with obvious frustration:

Nobody wants to pay for it [palliative care]. Obviously there’s no reimbursement for palliative care. And hospitals go to funders to fund different things like palliative care teams, or different projects to train nurses in the hospitals or to train physicians, and foundations are saying back to the hospitals that it’s their responsibility and then through the grapevine it’s like nobody’s going to take responsibility until they have to and so I think that everybody is waiting. The hospitals and the physicians are waiting until they have to do it, and nobody wants to fund it, nobody wants to pay for it.

Informant LL, who was relatively new to the field of palliative care funding at the time of the interview said, “Those two things [reimbursement and service provision] never seem to get put together and yet those are the two things that are driving. And, so my question is, are there opportunities out there in the field for those two things to come together to deliver holistic, integrated palliative care to patients?”

_Palliative care is not available or not part of overall care._

Funder informants who had experience in funding hospital-based palliative care were especially interested in moving into other areas where palliative care had not yet been advanced. Yet, as one informant recognized, those areas may be more difficult to penetrate then hospital-based palliative care. Informant EE said, “Home-based care proved to be even more difficult than work within hospitals. While hospitals have trouble changing things even within their own four walls, learning to play well with others is particularly difficult.”
Advanced planning has not reached enough people.

Advanced planning was also considered to not have developed sufficiently. As informant CC noted about distribution of proxies or advanced care directives for people who have entered the hospital or a nursing home, although it may be “mandated by law . . . it doesn’t really happen and when it does happen it’s often that someone gets handed a piece of paper to sign, but there isn’t real communication.” Informant AA expressed the feeling that the advanced planning movement was not properly focused, saying:

I think that certainly the support studies show that this whole movement toward advanced directives is kind of wrong-headed. We’re asking people to jump through all these hoops and say what they want to have done in a system that’s not very supportive. Instead we should really be telling people that if they want extreme measures they should let us know.

Private funding didn’t bring palliative care full-scale.

Several of the informants were critical of philanthropy for starting a movement and not taking responsibility for bringing it to fruition or planning it fully. Informant FF said:

I think that there was a swell of enthusiasm for it [palliative care], that everyone kind of hopped on board. And, I just think that the interest has dried up, people are on to the next big thing . . . and some of that was the success of the effort. It got attention, it ended up on people’s radar screen, on the public’s radar screen and foundations decided to declare victory and get out. I don’t think that they stayed in it for the long haul.
Informant JJ, a self-described local funder, said:

I think that what has not worked is big huge funders coming in and funding three- or four- or five-year initiatives and then dropping the ball and leaving everything hanging. And having the local funders try to help pick up the pieces when we haven’t been involved and we aren’t sure what’s a good model or which one out of all the initiatives will have the most impact and which ones we should keep supporting. That’s what I don’t think has worked. I think that while there’s been some good learning, it’s also left a lot of holes that local funders can’t pick up . . . and that’s again why we’re seeing more requests. But, people don’t talk to each other. They’re just trying different things and it’s difficult to hone in on what’s going to work in your community and who are the right players. It’s fragmented. There’s a lot of turf issues, personalities, and not enough resources.

Informant AA related an experience with a foundation that had seen palliative care as a real opportunity, but only wanted to fund it if they could provide extensive resources, and they determined that they wouldn’t do it unless they could make a significant impact: We estimated that it would take a full 10 years of funding . . . but that we could sort of build on the good work and help put some of these things over the top, and that it would initially require $15 million a year for five years.” But, Informant AA explained, they realized that they would have to add staff, that it could potentially detract from work already underway, and “that the worst possible outcome would be if [the board] said ‘Great, do it with your current budget.’ That would have meant that we would have been detracting from what we were already doing.” After careful thought and analysis they decided not to pursue it, Informant AA said.
Insufficient awareness/name recognition of palliative care.

Insufficient awareness of palliative care among the general public, and to some extent in the medical field, registered as one of the top issues for funder informants. Informant CC noted:

I think that engaging the public in an effective discourse about this [hasn’t worked]. I’m not sure that the every man has a healthy sense of their own wishes or how to communicate them. So, in terms of palliative care, knowing that it’s there – having it be top of mind for people. For them to say, ‘Oh, OK, it’s getting to this point in my chronic illness, and I’m not getting a lot of good care from my medical team. Maybe there’s an option for me.’ I think that people don’t generate that interest themselves and I would say that it’s a failing.

Informant II talked about the need for educating and empowering patients and their families:

I think that they [patients] really need to have the training and understanding of what it is and what their options are. And probably that goes to family also in terms of being able to assert what they would like to have, and what their loved one would like to have in terms of end-of-life care. And just the ability to say ‘Stop, that’s enough, they’re not comfortable, we’re going to do it a different way.’

Palliative care training still insufficient.

Informants expressed concern about pain and symptom management, and the lack of knowledge that among medical professionals about reducing suffering. Informant FF said, “Good pain management, good symptom control, utilizing psychosocial interventions, using alternative and complimentary therapies – I just don’t think people know how to do that.”
Capacity for measuring impact.

Funder informants registered opinions similar to those of the palliative care expert informants regarding assessment. The majority observed that it is difficult to quantify results of palliative care.

Table 43
Palliative Care Funder Perceptions of Capacity for Measuring Impact (N = 9)

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Measurement in palliative care is difficult</td>
<td>56</td>
<td>5</td>
</tr>
<tr>
<td>Simple things can be measured/satisfaction/costs</td>
<td>56</td>
<td>7</td>
</tr>
<tr>
<td>There is interest in development of measures</td>
<td>22</td>
<td>2</td>
</tr>
</tbody>
</table>

Measurement in palliative care is difficult.

Picking up a theme that recurred throughout the funder interviews, informant AA spoke specifically about trying to measure pain. “Pain is very difficult to measure. There have been some advances, very simple things like the pain scale.” Informant AA acknowledged that it is difficult to engage dying people in research. “It’s very intrusive; they have limited time, and they don’t want to spend it doing surveys, but I think that you could do things perhaps by talking to family members after the death and finding out what went wrong.”

Informant GG spoke to the concern that there is a lack of evidence to support a business argument for palliative care. “You know, where is the business case, where is the benefit? . . . I don’t think that beyond warm and fuzzy we’re doing it better, people like us. I don’t think that
that case has probably been made to a universal audience. To a small degree, but not a universal audience. It’s not something that’s assumed.”

Informant LL asked, “Can the field as a whole move to the next level and really figure out how to evaluate itself, and what’s most important, and by what criteria and who’s your audience for the results in order to change something? Is it a public education audience? Is it an audience of hospital administrators? Is it an audience of Medicare and Medicaid? Is the audience part of philanthropy?”

_Simple things can be measured._

Informant EE looked to the academic world to carry measurement of impact forward through its research. “The academic world is driven by research kudos, and if you can’t be doing research in palliative care it’s never going to gain the status that it needs in order to drive the change and train the next generation of clinicians.” Informant EE asked, “How about measuring the quality of care provided to someone who died in hospital X against those [established] standards? Did they get what they were supposed to get? Were they not inflicted with what they should not be? There really are standards now against which to measure that.”

Informant II discussed the importance to philanthropies of having ways to measure the impact of grant dollars. “We incorporate measurement into our grants. For example, on this residency training program we will be doing a pre- and post-survey of the residents going to the training, in terms of their knowledge. Then, I think that we’ll do a follow-up, or hospice will do a follow-up, to see how they incorporate the knowledge into their practice. So, it’s kind of small scale, but it’s a start.”
How the field has changed.

Among the top ways the field of palliative care has changed, informants mentioned greater awareness, more availability, and the emergence of committed leaders in palliative care. They mentioned again here that private funding is no longer as available as it once was. Table 44 presents these perceptions.

Table 44

Palliative Care Funder Perceptions of How the Field Has Changed (N = 10)

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>More people know about it</td>
<td>70</td>
<td>7</td>
</tr>
<tr>
<td>Palliative care is more available/more integrated into healthcare</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>Leaders have emerged/are committed to palliative care</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Private funding is no longer available to the same degree</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Palliative care is recognized as a medical specialty</td>
<td>20</td>
<td>2</td>
</tr>
</tbody>
</table>

More people know about it and there is more interest.

Informants thought that public awareness about dealing with death and dying is much greater than it once was, even though the term palliative care is not necessarily commonly known. Throughout the palliative care expert and palliative care funder interviews, informants mentioned a public broadcasting series created by documentary film-maker Bill Moyers. Informant AA said, "There is more awareness, in part because of projects like Bill Moyers' series 'On Our Own Terms.' It's a little bit like the whole birthing movement. Changes were
brought about because consumers demanded it.” Informant AA thought that additional consumer awareness would spark additional change. “If we have a more educated consumer base that can really bring about profound changes. We’ve seen some changes, and more needs to happen. But, it is heartening what has happened.”

Many informants thought that a change in attitude among the general population has occurred, and many attributed this to the Open Society Institute’s Project on Death and Dying in America. Informant EE commented, “We’ve come a long way in 10 years. You know, now it’s OK to talk about it. Soros [George Soros, founder of the Open Society Institute] was very clear that ‘death’ was to be in the title of his program. He wasn’t going to sweet talk it, and kudos to him for doing that.”

_Palliative care is more available/more integrated into healthcare._

Although many have criticized the philanthropic world for not carrying forward what was started in palliative care, informant EE said, “Those who put money into palliative care in the ‘90s ought to feel very good about it. They have started a movement, and that’s pretty remarkable. And this is not a long time for moving a system like our beloved healthcare system.”

Still some claim that despite significant advances, the field has failed in certain areas. Informant KK said, “When we first started our palliative care initiative, we had no idea what palliative care or palliative meant. Now it’s more common and I think it’s more accepted, but the term ‘hospice’ still means death sentence.”

Informant BB described the evolution from hospice palliative care, from a focus solely on death and dying to the management of chronic disease:
I think the other major change over the last several years – the last decade or so – is that the hospice at the beginning was essentially geared toward people who for the most part had cancer, and there are still some hospices in the country that only take care of cancer patients. But it has reached out into a lot of other areas – Alzheimer’s, AIDS, a number of other places to try and provide support – and they’ve found that some of that is problematic. For example, an Alzheimer’s patient. Hospice could do a lot for an Alzheimer’s patient, but they are limited to a scope of six months. Alzheimer’s patients and their families could benefit from a much longer stay. At the same time that they have created a lot of opportunity, they’ve found a lot of limitations. And a lot of it is related to the fact that there are some patients that cannot come onto a program early enough to really help them and their family as they should.

_Private funding is no longer available to the same degree._

In the category of what has changed, informants often discussed change in the funding landscape. Informant JJ said, “I think that palliative care is more on the radar screen in a lot of universities, hospitals, and hospices. So, there are more requests from good programs in desperate need, that won’t make it without foundation support. But the big funders aren’t there anymore, and we don’t know what to do.”

_Palliative care is recognized as a medical specialty._

The fact that palliative care was being recognized as a medical specialty was thought by some to be a sign that it would better be able to generate revenues. Informant EE said, “There
was a great deal of emphasis and a great deal of thought put into developing a subspecialty . . . so we will have yet another subspecialty that can drive some of the financing.”

*The palliative care agenda.*

Funder informants (Interview Group One) collectively identified an agenda for palliative care similar to that expressed by the palliative care expert informant group (Interview Group Two). Here again, top issues were raising awareness, training, making palliative care available, and making changes in Medicare and reimbursement. Table 45 relates these and other issues that were raised by the palliative care experts.
Table 45

Palliative Care Funder Perceptions of the Top Items for the Palliative Care Agenda

(N = 12)

<table>
<thead>
<tr>
<th>Item</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raising awareness</td>
<td>92</td>
<td>11</td>
</tr>
<tr>
<td>Training adequately</td>
<td>75</td>
<td>9</td>
</tr>
<tr>
<td>Making palliative care available/part of overall healthcare</td>
<td>33</td>
<td>4</td>
</tr>
<tr>
<td>Changes in Medicare/palliative care financing/reimbursement</td>
<td>33</td>
<td>4</td>
</tr>
<tr>
<td>Increasing collaboration among professionals/organizations</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Leadership development</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Development of palliative care tools for professionals</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Better management of pain</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Increased levels of research</td>
<td>17</td>
<td>2</td>
</tr>
</tbody>
</table>

*Raising awareness.*

Informant FF expressed what others had said in different words: “Disengage it from end-of-life and get people to understand its utility particularly for people with chronic disease. To see end-of-life care as a subset of palliative care, rather than palliative care being the equivalent of end-of-life care. That’s the top issue.”

Informant JJ said, “Another top issue is actually trying to clarify what palliative care is and having consumers, patients, and families and the general public understand so that they can
ask for palliative care services.” While none proposed in any detail a strategy by which palliative care could become better understood, informant DD remarked, “It’s something we’re all going to do [die], but we need to make it more like ‘Oh, we all take cholesterol medicine.’”

Training adequately.

Informant AA and a number of others asserted that training is the top priority. “Top priorities are people: building human capacity, including better training, stronger leaders, more leaders, stronger evidence base, better developed network, better rewards structure to support the people.”

Informant DD concurred. “Across the board we need manpower, training; and every one I meet with kind of says ‘Train them when they are in school,’ and so we need to get in the schools of nursing, social work, and medicine and start early.” While there was very little mention of training beyond doctors and nurses, informant CC mentioned pharmacists. “Training for pharmacists so they better understand pain management as well, would be another area.”

Making palliative care available/part of healthcare overall.

The need for systemwide change was mentioned by several of the informants. “One of the conclusions that we came to is that the healthcare system — and it seems like it might be obvious — is a portal through which everybody passes at some point who is going to die. So, if you can impact the healthcare system then that’s the way to go,” said Informant AA.

Informant EE recommended a three-pronged strategy for bringing about such change that included asking what providers would do differently; considering what “patients and families expect of the healthcare field, what they understand about their choices — and about altering the
choices that lie in front of them”; and the public policy agenda. Informant EE acknowledged that public policy is the most difficult of the three.

*Changes in Medicare/palliative care financing/reimbursement.*

While it would be almost impossible for most professionals in the field to imagine in Medicare, informant BB warned, “Most of the hospice money comes from Medicare reimbursement. But there is no guarantee that that carve-out will continue in the future. So, it’s very important that that [reimbursement and revenues] will continue to be near the top of the priority list.” Informant DD spoke of changing the hospice benefit so that it is a combination of hospice and palliative care, “because I think that most people psychologically can’t give up the hope of cure or care and don’t want to acknowledge that death may be imminent and so they end up in hospice when they’ve already been in pain and suffering.”

While it seems that most informants consider the Medicare issue to be almost insurmountable, Informant EE observed,

It comes back to a sense of some of the leverage we’re making with change would be from the payers. PC is not cheap, but if provided over the longer run, I got to believe its more appropriate care with higher quality. It is going to cost less if you keep folks out of ICUs and away from unnecessary hospitalizations. I would hope that the funders – and it’s predominantly Medicare and it’s Medicaid – really pay attention to what kinds of models do work, and where the models aren’t working. Maybe it’s not the model, it’s how it’s being implemented.
Better management of pain.

Pain and symptom management were mentioned frequently, and though it is considered one of the foundations of palliative care, pain management is still not as advanced as the experts think that it could and should be. This is due in part to research that has yet to be conducted, and also due to insufficient training for medical professionals. Informants reported that what has resulted is a system that unintentionally puts “people through a lot of agony that most people don’t want” (Informant AA). This is considered to be a top area for further improvements.

Regional grantmaking.

The funder informants had a significant number of suggestions for regional grantmaking efforts, and for grantmaking in general. Their recommendations were consistent with recurring themes, in particular raising awareness and training professionals. They provided substantial information regarding funding strategy, including a number of recommendations that had proven to be good investments for funders.
Table 46

*Palliative Care Funder Perceptions of Best Opportunities for Regional Grantmaking*

\[(N = 10)\]

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raise awareness (patient/caregiver/public/leader/medicine)</td>
<td>60</td>
<td>6</td>
</tr>
<tr>
<td>Train palliative care professionals</td>
<td>50</td>
<td>5</td>
</tr>
<tr>
<td>Fund strategically for lasting change/appropriate sized funding</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>Create new hospital-based palliative care programs</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>Support collaboration/affinity groups</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Create consumer demand and supply it</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Provide education about/development of advanced directives</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Support palliative care availability throughout healthcare</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Conduct research</td>
<td>20</td>
<td>2</td>
</tr>
</tbody>
</table>

*Raising awareness.*

Raising awareness was the most prominent theme encountered in throughout the research, even as it was recognized as being a strategic challenge and generally quite expensive to pursue. Informants identified potential key audiences as: the general public, medical and nursing professionals, civic leaders, business leaders, payers, and healthcare administrators.

Informant CC mentioned the work that had been done to develop the business case, “that shows that you actually don’t lose money by having people go into hospice.” Informant CC
continued, "I'd try to make sure that every hospital board of trustees and their chief financial personnel understand the business case. I think if you can get foundation CEOs to take a proposal to their boards, I think that they'll find out that there is a lot of interest."

Informant DD spoke more about the general public, not mentioning cost or specific strategy, but recognizing that there have been successful efforts in public education and that they are essential: "It is important to support communications broadly in end-of-life, including things like Bill Moyers kind of programs — really public-oriented education — and some innovative programs that would develop palliative care understanding."

**Train palliative care professionals.**

Several informants indicated that if only one thing was to be funded it should be training for professionals. "I would focus on programs that would train manpower," said Informant DD. "Try and get your schools like Berkeley, which has a great social work school, to make sure there's something in their curriculum about end-of-life for master's students."

While some assumed that basic understanding of palliative care is clear — what it is, what it means, what is involved — some informants say that assumption is a mistake that should not be made, and that education should be provided at every level and in every realm. "To nurses, to social workers, to practicing physicians, to hospital staff" said one informant, "because I think that often times they don’t understand what palliative care is."

**Fund strategically for lasting change.**

Funder informants discussed the need to fund strategically. They asserted an awareness that funds for palliative care are not as abundant as they once had been. While there did not
appear to be a shared agenda, they did express a sense of responsibility to invest wisely for the good of the regions and people that they served, and also for the ongoing development of palliative care.

The informants were acutely aware that most of them did not have grant dollars to invest on the scale that the Robert Wood Johnson Foundation and the Open Society Institute did.

"We're not the Robert Wood Johnson Foundation, and so do not have the resources to fund at the same level that they have," said informant LL, "But our use of challenge grants . . . it's basically a calling card for a group to use to approach another funder. It's a way to engage funders around something that's very concrete and I know that [one palliative care leader] is already doing that in California. Adding to that point, informant CC recommended collaboration. "Sometimes program officers at foundations can sell things at their organizations if they are partnering with other funders."

Create new hospital-based palliative care programs.

Speaking specifically of the Bay Area, informant CC said:

The first thing I would do is make sure that every single hospital in the Bay Area has some sort of palliative care service, which means getting key providers – nurses and doctors, clergy and social work staff, into training. And there is a big training program at the University of California San Francisco. The Bay Area is very lucky to have a good program that hospital teams can go through. I think that I'd try to make that available to every hospital at no cost.
Support collaboration and affinity groups.

Collaboration was a recurring theme throughout the interviews, recognized both as a basic tactic for advancing efforts and also as a good investment strategy for foundations. Talking about creating systems change, Informant DD said, “I might invest in something like a university palliative care leadership center. And I might make it possible for hospitals in that area which are interested to go to leadership training. If you’ve got 10 hospitals from the Bay Area who have a relationship with each other, they can help each other develop unique palliative care identity or specialties.”

Informant EE reinforced this idea:

If [you are a provider and] you want to do something to improve palliative care you want to do it collaboratively with your colleagues and with your competitors. Funders can provide extra resources . . . coaches and evaluators. We can put them at their disposal through a collaborative. This is actually quite within the reach of local foundations, but you have to create the buzz around it to make it go.

Create consumer demand and supply it.

One of the most striking ideas that was restated in a variety of ways is that funders should consider how they can stimulate demand to increase supply. Informant EE said, “Dealing with providers and helping the public understand the value and create greater demand for it will ultimately lead to the public policy agenda. Should hospice as a program be redefined? Do we want intensive care for all chronic conditions and not just terminal ones?”
Provide education about/development of advanced directives.

Informant CC said, “If I could focus on community, I think that I would do community-based work on advanced directives, where they go into senior centers and other places and really talk with people and help people think about identifying people and putting it in writing. It could be done through community organizations and churches.”

Support the availability of palliative care throughout healthcare.

Informant BB advocated moving hospice and palliative care into areas that are not currently served, that are less densely populated, or that are marginalized. Informant BB said:

The thing that they [hospices] haven’t been able to do is actually go into to smaller communities and be effective in providing hospice care to the smaller communities. I actually live in a small town, and they had a very small hospice in this small town that has about 30 patients. The CEO that came in three years ago began really talking about palliative care and working to get some resources into this community and some grants and now they take care of over 300 patients a day. It’s changed a lot of the way things are as far as palliative care and hospice care in this little mountain town because somebody was willing to do it and was willing to give some of the grant money that was needed in order to make some of the changes.

Another area that was recognized by several informants as being a good investment for maximum return, was funding for volunteer programs. Informant DD said, “Volunteers seem to be a core component of hospice and palliative care programs. Is there a way of getting more involvement as the need for hospice and palliative grows with the numbers of aging population? Can we better recruit, train, and retain volunteers?”
Conduct research.

Informants grappled with perpetual questions of how to influence policy, and how to conduct a demonstration project that will impact Medicare. Informant DD said:

I think that foundations can try things and do demonstrations, but foundations don’t stay in for 10 years. They want to see the results and see them disseminated. If foundations can get the word out about how palliative care can help hospitals’ bottom line that might influence the government. Improved care that also helps the hospitals’ bottom lines may bring the government to say to hospitals, ‘You have to have a palliative care consult team if government is willing to pay for and make it happen by legislation, regulation and certainly by money.’

Unfortunately, the foundation officers did not make more detailed recommendations on how to advance policy agendas.
Large-Scale Regional Grantmaking

Table 47

*Palliative Care Funder Thoughts on Large-scale Regional Grantmaking*  \((N = 10)\)

<table>
<thead>
<tr>
<th>Priority</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same priorities already mentioned</td>
<td>90</td>
<td>9</td>
</tr>
<tr>
<td>Raise awareness (leaders/medical profession/public/patients)</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Focus on quality of life issues</td>
<td>20</td>
<td>2</td>
</tr>
</tbody>
</table>

*Same priorities already mentioned.*

Asked if priorities would be different for large-scale grantmaking, Informant FF said, “I’m not sure that our priorities *per se* would have been different. The priorities would have been the same, which is to get it out of end-of-life care.” Informant FF then elaborated:

If I had a lot more money, I could expand the scope of what I was doing and I would probably expand it into a policy-making area. So, it might be doing work with the state around reimbursement policies. Thinking about how can we create an environment that enables practitioners to provide palliative care. Whereas there may be barriers now, so to try to create a hospitable environment for it through a policy-setting agenda. The other area I also might expand into is the consumer area – consumer information, helping them figure out how to access services, how to use services, things that they might be able to get.
Raise awareness.

Another area that was considered very costly, as mentioned before, was raising awareness. While there have been some very successful efforts and campaigns, it is something informants said needed to be approached with a great deal of money. Informant EE reinforced this idea and tied it to the problem of measuring impact:

One of the other things local foundations can do – but this is in the realm of more money and more time – and that is public education. I think that we still come up locally short of what people’s understanding of healthcare can and can not do for them is – what to expect of the healthcare system and how to be more effective advocates on their own behalf. That’s where I think that a community-based approach can really focus education and follow-through, if it’s tied in with some metrics that said how are we doing as a community with regard to end-of-life care . . . and come up, for example, with rates of what is unacceptable, whether it’s ICU transfers or admissions home to hospital transfers. We don’t have many tools. Having some community-wide report that asks, ‘Are we doing better?’ that asks, ‘Are we getting what we want for the community out of the healthcare system that is integral for the community?’

Research.

Again, addressing the public payer issues was seen as a gargantuan task and one that would be very costly. Informant EE said, “It’s a force that hasn’t been enlisted to date in a significant way – the payers. To get them there – and I think unfortunately it’s Medicare and Medicaid. How do you engage those two payers? That’s where you have to be big.” Getting at the same issue of public payers, Informant AA said, “I think one of the things would be to
support end-of-life policy scholars. I think that could be far-reaching and have a lot of impact. There’s not a lot of attention being given in that area.”

*Development of palliative care for skilled nursing facilities.*

Informants recognized that skilled nursing facilities are becoming a focus for the field, but also recognized that they are difficult to work in because of the rapid turnover and other challenging issues. However, Informant AA commented, “Anything that you did in that area that was an advance would be really pioneering because almost nothing is being done there.” Informant CC spoke more specifically. “I would get training for every director and key staff in the nursing homes. I’d make sure there were strong relationships between nursing homes and hospice.”

Informant GG envisioned training, “a whole cadre of nurses to be palliative care nurses and not just for nursing homes, but [also for] residential care facilities for elders in this state, which have grown by 25 percent in the past 10 years and have more people in them than are in nursing homes.” Informant GG continued:

So, if money were no object, I would help alleviate the nursing shortage by funding a program that would bring interested, capable, and compassionate people through a nursing training program, train them as palliative care nurses working specifically in long term care to really help families and residents, individuals, make the best choices possible to have the kind of life that’s worth living until the end, and have the kind of death that is peaceful and supportive. No one will ever fund that.
If money were no object at informant organization.

Table 48 conveys informant responses to the question, what might they focus on if money were no object at their organization? Some of their responses are included under the previous heading (Large-Scale Regional Grantmaking). Again here, informants indicated that policy and raising awareness, along with research, would be priorities if larger sums of grant funds were at their disposal.

Table 48

*If Money Were No Object at Palliative Care Funder Informant Organizations (N = 10)*

<table>
<thead>
<tr>
<th>Category</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policy development related to palliative care/Medicare</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Raising awareness of public and professionals</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Research</td>
<td>30</td>
<td>3</td>
</tr>
<tr>
<td>Further development of existing programs</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Training</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Making palliative care available/part of overall healthcare</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Support for families and caregivers</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Development of palliative care for skilled nursing facilities</td>
<td>20</td>
<td>2</td>
</tr>
</tbody>
</table>

Visions for palliative care.

In stating their vision for palliative care, funder informants, as well as palliative care expert informants, focused on the availability of palliative care for all and throughout the
continuum of healthcare. Palliative care expert informants focused secondarily on issues of spirituality, while the funder informants focused on Medicare and other policies. Table 49 conveys these differences in emphasis.

Table 49

Palliative Care Funder Visions for Palliative Care (N = 9)

<table>
<thead>
<tr>
<th>Vision</th>
<th>Percent</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care would be available to all, throughout healthcare</td>
<td>78</td>
<td>7</td>
</tr>
<tr>
<td>Medicare and other policies will support palliative care</td>
<td>44</td>
<td>4</td>
</tr>
</tbody>
</table>

Some of the visions were based on long-standing dominant care belief about basic needs of human beings. For example, Informant AA paraphrased from the Institute of Medicine’s Review of Death in America, “If I remember correctly, they said that a decent or good death is one that’s free from avoidable distress and suffering for patients, families, and caregivers, and that it’s in agreement with patient and family wishes.”

Some suggested that society needs to return to a simpler and more neighborly way of living, “We’ve become much more separate,” Informant BB said. “Families live thousands of miles away and there’s not as much time to even know your neighbors in the community. I think that one of the goals of hospice has been that people would work together as a community and I think that that’s one of the things that I’d love to see in the future – that we come back to something that was done 100 years ago.”

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Informant CC had a quantified and time-specific vision. “Right now about 22 percent of hospitals in California have palliative care services, but we’d like to see by 2010 that 50 percent have them, and by 2015 that all hospitals have them, including safety net hospitals where they don’t exist much at all.”

Informant FF addressed the need for continuity and effective care, so that “palliative care becomes integrated within regular healthcare services and used effectively. Also that it doesn’t become dichotomized, that it becomes completely integrated with curative services, that we use them seamlessly and conjointly.”

Expressing the desire for knowledge and availability for all, Informant GG stated, “Any time, any where, from anyone qualified. I think it needs to be completely integrated and accessible and available and people need to know about it.”

Medicare and other policies will support palliative care.

Informant JJ spoke of integrating palliative care with all of healthcare, supported by appropriate reimbursement: “My vision for palliative care is that it becomes a seamless part of our medical care, that it’s not curative versus palliative, but that it’s immersed in the way that people receive their medical treatment, and it’s just a natural extension, and that there’s reimbursement for it.”
Chapter Four: Summary and Conclusions

Review of the Problem

For more than 30 years, hospice has provided end-of-life care to patients and their families through a model of care that includes conventional medical care, pain management, spiritual support, psychological counseling, and case management. This interdisciplinary coordinated care model, which evolved principally through hospice, is known as palliative care, and for many years it was reserved for those whose physician could certify them as six months or less from death. Over the last decade, a movement has emerged to extend palliative care not only to those whose death is imminent, but also to others who are in need of this range of simultaneously delivered intensive services. Such individuals generally suffer from a chronic disease, which will eventually be terminal, but that is not expected to cause death within a predictable range of time. Palliative care has been shown to relieve the suffering of those living with a chronic illness, and to help them to achieve a higher quality of life. There are also many who are working in the field that believe that it saves financial and human resources, though, as one participant pointed out, this is very complicated and there is no definitive information on this.

A field known as palliative care has emerged, and its development was supported over a period of more than 10 years, through more than $200 million in grants made by two major private foundations. Because of that funding, the field of palliative care developed extensively, if only in pockets, around the United States. Today, palliative care is a medical subspecialty and there is a movement to bring it to every healthcare arena. Yet with the end of those major grantmaking initiatives extensive funding gaps emerged and much unfinished work remains.
It is widely recognized by experts and practitioners in the fields of palliative care and hospice that existing policy, the healthcare establishment, and government administration continue to impede the effective use of both palliative care and hospice. It is also recognized that continued efforts to promote palliative care on local and regional levels are essential if the benefits of reduced human suffering and potential financial savings are to be maximized.

To the knowledge of this researcher, and based on the literature review conducted for this study, no extensive effort has been conducted to expand palliative care within one geographic region of the United States. Nor is there published literature or a study that describes knowledge of palliative care and opportunities and willingness to advance palliative care efforts in the Bay Area. These conditions raised questions that are the basis for this study.

**Discussion of the Findings**

The primary research conducted for this study revealed opportunities and significant barriers to the advancement of palliative care in the Bay Area. The research also identified opportunities for strategic grantmaking in the region – and in general – based on current priorities expressed by Bay Area healthcare professionals, and foundation professionals from around the United States.

The research revealed substantial knowledge of palliative care and interest in its advancement among Bay Area healthcare professionals at organizations that currently conduct or could conduct palliative care. It also highlighted significant barriers to the advancement of palliative care, mostly in the form of inadequate resources, both financial and human. The research indicated that the leading priorities for a significant number of healthcare foundations that conduct grantmaking in the region are compatible with palliative care in a broad sense.
However, their representatives claim limited knowledge of palliative care, and most indicated that the organization they represented would not consider making palliative care grants in the near future.

Interviews conducted with palliative care providers, funders, and other experts in the field revealed lessons learned, current priorities, and recommendations for the advancement of palliative care and related grantmaking, most of which fell under the following overarching categories: (a) general awareness of palliative care; (b) development of needed human resources in palliative care; (c) changes in prohibitive reimbursement structures; (d) increased and appropriate support for patients and families; (e) development of better pain and symptom management; and (f) availability of palliative care to all (including culturally competent care), across all healthcare settings.

Summary of Results

This section of Chapter Four provides a summary of the information learned about the current field of palliative care, about funding opportunities in the Bay Area and beyond, and about the visions of palliative care experts interviewed for this study.

The Healthcare Organization Survey gathered information from respondents at Bay Area organizations that fall within a broad range of sizes, with annual budgets ranging from $850,000 to $33 million. About half of the respondents perceived palliative care to be the focus of or a substantial part of their work, while the other half reported that palliative care plays only a small role in their work. About one-third of the respondents have been working in palliative care for two years or less, a third for under 10 years, and another third has been working in the field for more than 10 years. The primary services in palliative care that are provided at Bay Area
healthcare organizations are in-patient and consultative services. These results demonstrated a relatively small base of palliative care practice, but one that appears to be very strong and growing.

Most of the respondents said that they understood a great deal about palliative care and indicated that they understood the difference between palliative care and hospice. Most believed that existing medical systems only sometimes meet the needs of patients, even though palliative care is thought to cost less than care provided by existing systems used to care for those that need palliative care. Most contend that palliative care could be implemented within the parameters of current reimbursement structures, while a small minority asserts that it is almost impossible. About 42 percent indicated that palliative care could save their organization money, and close to one third indicated that it could increase their revenues.

The majority claimed that their patients, or clients, would benefit from a palliative care program, and that there are specific palliative care-related areas that exist currently at their organizations that they could expand to provide better care. All of the respondents said that palliative care supports or would support their mission. The top areas that they thought it would support are the management of pain and symptoms; improved communication and decision-making for patients, families and care providers; and facilitation of beneficial care that reduces costs.

In general, they claimed that significant barriers exist, such as lack of financial and human resources, but that there is some existing capacity and that their foundation boards probably would support the development of new or expanded programs. A small percentage (9 percent) reported that the administration of their organization would not support palliative care programs. Yet for most of them, existing capacity within their organizations currently includes
mostly medical, nursing, case management and spiritual support expertise. Most indicated that their organizations are ready, or somewhat ready, to receive grants related to palliative care. They all indicated that they are either very interested or somewhat interested in learning about palliative care.

The foundation survey involved Bay Area foundations that conduct grantmaking in the three focus counties. Their asset bases ranged in size from $1.5 million to $6 billion, and they reported annual giving from $850,000 and $230 million. The most frequently reported grantmaking priorities were access to healthcare and elimination of health disparities.

Most of the foundation respondents indicated having some knowledge of palliative care, including knowledge of specific palliative care work in the United States. However, the results indicated that most are not completely certain of the difference between palliative care and hospice, which demonstrates a significant lack of understanding about the emerging field of palliative care.

A small number of funders indicated that they have provided support that is related to palliative care, mostly in hospice, general operations, and training and education. However, most indicated that they are not likely to make palliative care, end-of-life, or hospice grants this year. The majority indicated that if they were to make grants in palliative care that they would most likely support direct services and skilled nursing facilities. A small percentage of respondents indicated that they would make grants in several other palliative care related target areas, such as advocacy and awareness, collaborations, demonstration projects, family caregiving, leadership training, general palliative care, and training and education.

The findings from the two interview group – funders and practitioners - and analysis of the transcripts for latent content, revealed a dominant set of themes. These are: (a) general
awareness of palliative care; (b) development of needed human resources in palliative care; (c) changes in prohibitive reimbursement structures; (d) increased and appropriate support for patients and families; (e) development of better pain and symptom management; and (f) availability of palliative care to all (including culturally competent care) across all healthcare settings. These themes are echoed in current palliative care research and are central to the palliative care movement.

The data organized under those dominant themes described: ongoing gaps in care; evolving capacity for measuring impact; efforts that have worked; efforts that have not worked; a collective agenda for palliative care; and ideas about how the field has changed. It also provided descriptions of opportunities for advances in palliative care in the Bay Area and in the field in general as well as recommendations for related grantmaking. Finally, the interviews provided descriptions by the informants of their visions for the future of palliative care.

The 12 palliative care experts who participated in Interview Group One expressed a wide variety of perspectives and opinions as well as a variety of palliative care professional posts and types of organizations. Most of them participate directly in the care of patients and their families; a large percentage of them have conducted research projects; and several of them have published extensively on the subject of palliative care.

The 12 informants who participated in Interview Group Two, represented philanthropic institutions from around the United States with experience in national, regional, and local grantmaking in palliative care on a variety of scales. Some of them were relatively new to the field and others had worked in palliative care for many years. They represented a broad range of perspectives, and most held strong opinions about what has worked, what has not, and best potential strategies for grantmaking in palliative care.
Interview Group Two provided more extensive insight into strategic grantmaking, laying out a couple of specific outlines for a grantmaking approach and offering a variety of specific suggestions for grantmaking in the Bay Area, in other regions, and for palliative care in general.

The interviews revealed that there are some new funders working in palliative care, which have indicated that they will commit fairly substantial resources. However, they also reinforced the fact that sharply diminished grant dollars to the field is a major problem. Related to this there are some feelings that funders have behaved irresponsibly in moving into such an important area and then withdrawing to leave programs at a time when they don't have a plan to keep the work going - and there is concern that this will potentially stall the movement of palliative care. The funder informants who participated in Interview Group Two were especially focused on this, implying a sort of discomfort about the actions of their funder peer group and annoyance with those that have left the field.

The vision for palliative care most frequently expressed by palliative care experts and funders who participated in the interviews was that palliative care would be available to all who need it, that it would be available through the continuum of healthcare, and that it would be reimbursable. Most envisioned that reimbursement mechanisms, primarily Medicare, would be changed to support palliative care more fully. The funders were less concerned with spirituality than the palliative care experts and focused more on practical aspects of care, such as changing the field via policy and education, and raising levels of public awareness.

Conclusions

Development of the field of palliative care, which was initiated and nourished through extensive funding over more than a decade, has to some extent been slowed because of sharply
reduced funding, a lack of understanding by the general population, and the inaction of major institutions. Although research supported by extensive private donor investments provided evidence that a reduction in human suffering, and potentially cost savings, can be achieved through palliative care, healthcare organizations, government agencies, and policy makers have largely failed to make necessary changes to support it. This was revealed repeatedly through the data and quotes collected for the study. However, also revealed through the study are the facts that palliative care is still developing, that leaders in the field have emerged, and that many patients and their families continue to benefit from it. Most importantly for the topic of this study, the data indicate that the opportunity for strategic grantmaking investment that will provide measurable returns, especially in reduction of human suffering, is as tangible as ever.

A significant base of existing palliative care services, or related healthcare services on which palliative care programs could be built, exists in the Bay Area. Such palliative care programs would substantially increase the ability of Bay Area healthcare organizations to meet the needs of patients and their families, support their organizations’ missions, and improve their financial stability. The dominant barriers that would have to be overcome are a lack of financial and human resources. These barriers are not prohibitive, however, because some financial resources are currently available for such work, expertise already exists, and successful models and related data are available. Support organizations and networks are in place for those who are developing and conducting such programs. Primary areas that were indicated for development include pain and symptoms management, and communication and decision-making for patients, families, and care providers.

While a significant number of healthcare funders are working in the Bay Area, a significant lack of understanding regarding the characteristics of palliative care and its potential
for positive impact constrains them. Although a small number of Bay Area funders have provided support that is related to palliative care – mostly in hospice, general operations, and training and education – they are not planning to increase such work to any large extent. This study found only one exception to that pattern. Although precise details were not yet available there is one funder that will potentially make investments in the multi-million dollar range over several years.

Even though most of the Bay Area funders who participated in the Foundation Survey indicated limited knowledge of palliative care, and it is unlikely that they would make grants in this field, their general grantmaking priorities and guidelines are not incongruent with palliative care. Palliative care is relevant to the dominant grantmaking categories that were reported, including access to care and health disparities. Foundation officers also indicated that, while existing foundation priorities would be guiding factors in their decision-making, public priorities would also play an important role. It appears that a lack of knowledge and understanding, and a lack of public demand, have kept this field from receiving more serious consideration.

The information gathered through the two groups of interviews reinforced an ongoing understanding that support for patients and families at times of great crisis is insufficient, that pain and symptom management is unnecessarily inadequate, and that these shortcomings could be changed. However, the same research suggests that these services are all possible through public awareness, appropriate training for professionals, implementation of proven models of team-based care, and changes in reimbursement structures.

Patients and families experiencing great duress because of acute pain and symptoms of chronic illness, or who are at the end of life, are too often provided with inadequate information through lack of appropriate communication and support from the professionals who serve them.
This undesirable circumstance is due mostly to the fact that patients and families have not demanded such care, and also because professionals have rarely been trained to provide it. The end result is that patients and their families too often spend the last years and days of their lives in pain and distress.

Healthcare professionals who participated in the study who have been trained in and have practiced palliative care, explained the significant improvements that can be achieved in the quality of life for patients and families, and their own satisfaction in providing such care. They also expressed their ongoing frustration with their inability to provide appropriate care.

The funder informants, who had all supported palliative care to some degree, expressed an awareness of the benefits of palliative care as well as frustration at not being able to provide more substantial support for the field. Interestingly, they indicated higher levels of disappointment and frustration with their field and their peers for not having continued to sustain or initiate new support for the field than the healthcare professionals who were interviewed.

A number of the participants in the interviews touched on issues of spirituality and the need for the evolution of society toward higher levels of acceptance and understanding of death – and of the need for better support from healthcare professionals on a human and spiritual level for those who are chronically ill or dying, and for those whose loved ones are in that situation. While both the palliative care experts and the funders who participated in the interviews demonstrated concern in this area, the palliative care experts placed it higher on their collective list of priorities. Funders expressed more interest in changing society’s systems. This probably can be attributed to the fact that palliative care experts have regular contact with chronically ill and dying patients, while funders generally do not. The funder survey data indicate very little
interest in this area, which may reflect society’s aversion to dealing with matters related to aging, sickness, and death and to the medical field’s determination to resist death at all costs.

The overarching conclusions of this study point to strong recommendations for advancing palliative care through grantmaking across regions, and in general. These conclusions were derived from both interview groups and supported by data from both surveys. Many of the specific recommendations, outlined in the results section of this study, indicated the need to increase consumer demand for palliative care through increased public awareness. Interview participants collectively suggested that better public knowledge about palliative care options will lead to an increase in demand, and consequently lead to additional programs in palliative care and corresponding training for healthcare professionals. They also suggested that this would ultimately lead to long-needed changes in reimbursement and an increase in quality of care, pain and symptom management, and the availability of palliative care throughout the healthcare system.

Some of the informants discussed the essential need for ability to measure impact of palliative care in bringing change. Informant opinions in this area suggest the need for more focused development. Their collective comments suggest that measurement capacity currently exists which can demonstrate cost savings and certain elements of improved quality of life and death if used more systematically.

These recommendations are congruent with the indication of capacity for and interest in advancement of palliative care at Bay Area organizations that was represented in the survey of healthcare professionals. Based on the information they provided, and on the testimonials of palliative care experts about models that work well, there is very little doubt that effective palliative care programs, could be successfully replicated across the Bay Area, and in other
regions. While specifics of the Bay Area, or any region that would host a range of palliative care programs would be essential to the design of a grantmaking strategy to advance palliative care in that region, there is reason to believe that such grantmaking could measurably reduce costs. However, it should be noted that government regulations, developing public policy, and corporate involvement in the arena will play a large role. Grants for this purpose could significantly improve the lives of the citizens of the region in ways that could be measured, as well as in ways that are not as easily measured.

Informants were asked about the measurement of impact of palliative care in part because a growing number of philanthropists seek to base their selection of grant recipient projects and programs on their ability to demonstrate significant return on investment. A great deal of information was provided by the informants about what can be measured in the delivery of palliative care. Yet, as Informant J pointed out:

One of the biggest practical challenges in palliative care programs is proving the negative and that is incredibly difficult to do. A metaphor I might use . . . You can put someone on a blood thinner, they don’t get a heart attack, they don’t get a stroke. If you’re in a real hospital proving how many strokes you prevented in 50 patients is not only difficult, it’s impossible. You can’t prove it in those people – you need a research design, and yet many of the palliative care programs are being told to prove that they saved this money. So, many of programs are struggling. Some of them don’t even recognize that they are being asked to prove a negative – when no one knows how to do that. That’s a big challenge.

Development of increasing capacity for measurement of the impact of palliative care is clearly important to the field. However, funders who choose to raise levels of quality for the
terminally ill or dying will, at this point, have to accept somewhat limited measurement and the testimonial about what works from dedicated professionals with years of experience. They may also choose to provide support for the ongoing development of tools for measurement.

The vision of Informant F for the field of palliative care, speaks to this concern:

My vision for palliative care is to see a discipline, or a community, or network of providers across settings where we can really link hospice and the rest of the medical system together and create a real continuum of care particularly for elderly patients with advanced illness. But, I would also put in there that I think that we’ve paid a price—everything that we’ve talked about so far has been on the operations level, the financing level, or the outcome measurement level. All those things are well and good, but what often gets left out, or what usually gets left out on those levels are the intangibles, like the spiritual aspects of the struggles that patients and families go through for meaning near the end-of-life and the despair that a lot of patients and families go through when they get seriously ill and when one of them is dying and there is nobody around who is willing to speak or even able to speak to people about what they are actually going through in their hearts. My vision would be that we develop a vibrant, robust, strong language for dealing with suffering and despair toward the end of life. You know, we just slap a label of depression on it and try to measure it and throw drugs. And that’s not what it’s about, it’s about finding ways to deal with spiritual suffering and to provide better and better support to—just the healing power of presence—to really begin to study and look at what it means to be present sitting face to face with somebody who is suffering and being able to provide the quality of presence that allows people to know that they’re not alone in their torment, they are not abandoned. We’re terrible at that. Even in palliative care we
have a lot to learn, but particularly in medicine as a whole, we abandon patients and families all day every day – and especially all night every night. It's the dark night of the soul for most patients who are sick and dying and we don’t even have a language to express where the needs are there – so we need to develop that more fully.

This statement speaks to the need for palliative care, recognizes the importance of measurement, and points to the enormous need to prepare healthcare professionals to deal with the most difficult moments that their patients, their patients’ families, and they, will face. It highlights a glaring gap that has been addressed by some funders over the last 15 years, and it reminds us that the gap still exists, that we now have the tools to fill it, but that it will take the support of entire communities – and that funders can play an important role in gathering that support. It leaves us to consider the call for greater understanding of spiritual needs related to dying and death for patients, families, healthcare professionals, and an entire society. Finally, it assures us that there are professionals working in the field who understand the complexity of the situation at hand, who are dedicated to improving it, and that we must “really begin to study and look at what it means to be present sitting face to face with somebody who is suffering” and be “able to provide the quality of presence that allows people to know that they’re not alone in their torment – they are not abandoned” (Informant F).

Palliative care and hospice strive to accomplish this in increasing ways. There is currently abundant opportunity for funders to make dramatic impact with relatively small investments, largely because the field has come so far, and because substantial models exist.
Implications of the Study

Implications for Literature

While some literature is available on philanthropy’s role in the implementation of palliative care programs and on the development of the palliative care field, it is limited. This study addressed specific issues related to existing palliative care and the potential for its advancement in one region as well as general issues in the advancement of palliative care and related grantmaking. The study provides a current assessment of top issues and opportunities in this area of healthcare and philanthropy at the point in time at which the primary research was conducted (August 2006). Research that combines information about one region with the opinions of experts from across the country did not exist before this completion of this study.

Practice Implications

The study presents findings that can be used by funders who work in the Bay Area, as well as by funders who work in other regions of the United States. It also can be used by organizations in the Bay Area or other regions that hope to establish programs in palliative care or advance existing palliative care efforts. The current need for palliative care, the positive impact of it, and the best opportunities for advancing it as they relate to philanthropic efforts are detailed in this study. Grantmakers and those seeking grants in palliative care can use specific recommendations from this study along with data from their own grantmaking priorities and geographic specifications to develop their strategies.
Policy Implications

While many hospice and palliative care healthcare professionals and organizations have managed to work within the parameters of existing systems, which are regulated by current national policy, it remains a significant challenge for the field. Discussion of the state of palliative care in the United States inevitably leads to extensive consideration of Medicare and Medicaid policies, as well as the policies of other payers, which have limited to a large extent the ability of the healthcare system to provide appropriate care to patients. The research presented here could be useful to funders or others considering the need for changes in policy related to hospice and palliative care. However, as noted by several of the experts who were interviewed, policy change is one of the greatest challenges that funders can address, and it was mentioned as one of the things that funders would do only if extensive funds were available.

Opportunities for Further Study

Possibilities for funding across one region to impact change in the delivery of healthcare is a subject which could be pursued by an entire team of researchers. For example, the array of relevant institutions in the region, policy factors unique to that region, and its demographics could all be studied in great detail.

Also, as noted in the limitations section of Chapter Two, the sample for this study was non-random and non-representative, and was not of sufficient size to form definitive conclusions. A study that incorporated random and more highly representative survey respondents could strengthen the results significantly. If additional time and financial resources were available, this would be possible. The study would have benefited greatly from the participation of additional respondents and informants. In order to achieve this, the involvement of an affinity group
References


Appendix A

Articulated Needs for Palliative Care Policies

Summarized from Davies & Higginson (2004):

1. Palliative care should be available to people of all ages who are living with and dying from a range of serious chronic diseases; and should be a core part of health care.

2. Identification of common serious diseases including cancer, ischaemic heart disease, cerebrovascular disease, chronic obstructive respiratory disease, end-stage liver and kidney disease, infectious diseases and dementia.

3. Identification of people living with serious chronic illnesses in widely different settings such as the community, nursing homes and hospitals, including intensive care.

4. Support families and caregivers in their efforts to care for the patient and to cope with the sense of loss that the illness brings. This might include assistance similar to that often granted to those with maternity and paternity responsibilities.

5. Services more widely and broadly offered and integrated across all health services.

6. Services available on the basis of need in terms of symptoms and problems, and their effectiveness in meeting that need, rather than on the basis of diagnosis.

7. Public health policy must acknowledge people’s right to high-quality palliative care and to make decisions about it, whatever the nature of the disease they suffer from. These rights should be enshrined in health and social care legislation.

8. Policy-makers should monitor the wishes of seriously ill people concerning place of care and death; and concurrently monitor place of death as one interim measure of success of the system of palliative care provided.

9. Development of palliative care skills in staff working across all settings, especially in pain and symptom control and communication.

10. Palliative care services coordinated across different settings of home, hospital, inpatient hospice, nursing home and other institutions.
11. National systems to monitor access to palliative care for all groups in society; and for monitoring and improving the quality of services provided to these populations.

12. Rewards for health care organizations that engage in audit and quality improvement schemes in palliative care.

13. Dissemination of examples of good practice and constantly review the success of these methods in palliative care.

14. Demonstrations of innovative approaches and evaluation of their merit in palliative care need to be widespread and encouraged.

15. Palliative care as a core part of the training and continuing professional education of doctors, nurses, social workers, chaplains and other health professionals. Sufficient palliative care specialists trained and supported to provide this education.

16. Development of health care organization cultures and working practices that allow the best use of the palliative care skills of health professionals, including spending sufficient time with patients and families.

17. Public education designed to increase awareness of palliative care issues.

18. Policy-makers need to develop national strategies for palliative care research, and to expand investment in this area across all diseases, and including development of national data sets for palliative care.

19. Those funding research should monitor the proportion of funds in any disease area directed towards palliative care, and invest in research to redress imbalances. They should also encourage innovative research to help people with serious chronic illnesses to live well and die well.
### Appendix B

**San Francisco Bay Area Palliative Care Providers**

<table>
<thead>
<tr>
<th>Provider</th>
<th>County</th>
<th>Sector</th>
<th>Org Size</th>
<th>Revenues</th>
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<td>SF</td>
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</tbody>
</table>

**LEGEND:**

NP = Nonprofit; PRIV = Private or For-profit; GOV = Government
Appendix C

Healthcare Organization Survey

1. Which of the following statement best describes your organization’s work in palliative care?
   - Palliative care is the focus of our work
   - Palliative care is a substantial part of our work
   - Palliative care plays a small role in our work
   - Palliative care is not a part of our work

2. Which of the following best describes your understanding of the difference between hospice field and the palliative care field?
   - The difference between the terms is very clear to me
   - I have some understanding of the difference
   - I see them as related, but separate
   - I have no idea what the difference is

3. Which of the following time spans best describes the amount of time that your organization has been working in palliative care?
   - Over 10 years.
   - From 5 to 10 years
   - From 2 to 4 years
   - Less than 2 years
   - None at all

4. Which of the following best describe your organization’s work in palliative care? (Please check all that apply)
   - Improving patient outcomes through expert pain and symptom control
   - Expediting communication and decision-making for patients, family members, and health care providers
   - Increasing coordination among health care providers
   - Easing patient transitions between care settings
   - Reducing the burden of time-intensive and complex cases to improve staff satisfaction and retention
   - Applying a more systematic approach to outlier (long length of stay) patients
   - Promoting beneficial care, resulting in more appropriate use of hospital resources and cost avoidance, and improved palliative care capacity
   - Other (Please indicate in the box)____________________
   - Not applicable
5. Which of the following best describe areas of work in palliative care that your organization would like to advance to a significant degree, if it were to focus on three of the items listed? (Please choose only three.)
   - Improving patient outcomes through expert pain and symptom control
   - Expediting communication and decision-making for patients, family members, and health care providers
   - Increasing coordination among health care providers
   - Easing patient transitions between care settings
   - Reducing the burden of time-intensive and complex cases to improve staff satisfaction and retention
   - Applying a more systematic approach to outlier (long length of stay) patients
   - Promoting beneficial care, resulting in more appropriate use of hospital resources and cost avoidance, and improved palliative care capacity
   - Other (Please indicate in the box) ____________
   - Not applicable

6. In order to advance palliative care efforts in any of the areas listed above, which of the following are key areas that you need to focus on? (Please check all that apply)
   - Advanced Directives
   - Advocacy/Awareness
   - Bereavement Services
   - Collaborations
   - Conferences
   - Demonstration or Pilot Programs
   - Direct Services
   - Dissemination
   - Ethics
   - Family Caregiving
   - Fellowships
   - Hospice
   - Leadership Training
   - Legal Issues
   - Operating Support
   - Policy
   - Professional Education
   - Program Evaluation
   - Program Replication
   - Public Policy
   - Religion
   - Research
   - Rural Issues
   - Spirituality
   - Support of the Arts related to chronic illness or death
• Symptom Management
• Technical Assistance
• Therapies (massage, music, etc.)
• Training and Education
• Volunteers
• Other, please specify ______________

7. Which of the following describes what your organization is set up to do in palliative care? (Please check all that apply)
   • Consultative services
   • Inpatient services
   • Outpatient services
   • Not applicable

8. Which of the following best describes barriers keeping you from advancing palliative care at your organization? (Please check all that apply)
   • We don’t have the financial resources
   • We don’t have the human resources
   • Our administration will not support it
   • Our board will not support it
   • Our mission will not support it
   • It doesn’t make sense for us
   • Other, please specify________________________

9. Which of the following best describes the financial viability for advancing palliative care at your organization?
   • We currently have the financial resources
   • We have some resources, but not enough to do what we’d like to
   • We have very few resources to do what we’d like to
   • We have no funds to expand what we currently do

10. Which of the following best describes the operations capacity for advancing palliative care at your organization?
    • We currently have the capacity
    • We have some capacity, but not enough to do what we’d like to
    • We have very little capacity to do what we’d like to
    • We have no capacity to expand what we currently do

11. Which of the following best describes your organization’s readiness to take on new projects in palliative care if the organization was awarded a grant to do so?
    • We are well poised to receive a grant and carry out a new project in palliative care
    • We are somewhat ready to receive a grant and carry out a new project in palliative care
• We would have to implement a number of things to be prepared to receive a grant and carry out a new project in palliative care
• We could not be ready at this time to receive a grant and carry out a new project in palliative care

12. Which of the following best describes the extent to which palliative care work supports (or would support) your organization’s mission?
• It clearly supports (or would support) our mission
• Though not primary to our mission, it supports (or would support) our mission
• It does not (or would not) support our mission at all

13. Today there are more patients with long-term complex and chronic illnesses that require complex management and support. Which of the following best describes the capacity of existing medical systems that you are aware of to provide this management and support?
• Existing systems always meet the needs of patients
• Existing systems sometimes meet the needs of patients
• Existing systems never meet the needs of patients
• I don’t know enough to express an opinion
• I know nothing about it

14. Which of the following best describes your perception about the cost-effectiveness of palliative care?
• Palliative care is much more expensive than that which is provided by the current predominant systems
• Palliative care costs just about the same as that which is provided by the current predominant systems
• Palliative care costs less than the care which is provided by the current predominant systems

15. Which of the following best describes your perception of current payers systems (Medicare, Medicaid, private payers, etc.) and their interface with palliative care?
• Palliative care can work well within existing payer systems
• With some maneuvering Palliative care can work within existing systems
• It is almost impossible to offer palliative care within existing payer systems
• It is not possible to offer palliative care within existing systems

16. Which of the following best describes your understanding of recent best practices in palliative care work in the U.S.?
• I know a great deal about what has been done in this category
• I know that some work has been done
• It sounds familiar, but I don’t really know much about it
• I have heard nothing about it

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17. Which of the following best describes your organization's capacity to collaborate with other organizations on the delivery of palliative care?
   - We are very well situated to develop collaborations in palliative care delivery
   - We are somewhat situated to develop collaborations in palliative care delivery
   - It would be a stretch for us to develop collaborations in palliative care delivery
   - We are not situated to develop collaborations in palliative care delivery

18. Please indicate which of the following your organization is equipped with for palliative care, or potential palliative care efforts (Please check all that apply):
   - MD and RN clinicians with interest and/or training in palliative care.
   - Relationships or contracts with other organizations that focus on palliative care
   - Case management
   - Chaplaincy program
   - Palliative care interest based on personal or professional experience
   - Pain services
   - Computerized medical records
   - Community interest in and support for palliative care
   - Trustee or board or philanthropic interest in palliative care

19. Please indicate which of the following apply to your organization (Please check all that apply):
   - The organization has a patient/client population that would benefit from a palliative care program
   - The organization currently provides services that could benefit from collaboration with a palliative care program
   - Pain and symptom distress scores for patients with life-threatening conditions show room for improvement
   - Staff satisfaction survey show staff stress related to perceived understaffing for the treatment of patients with life-threatening illness
   - A palliative care program could save the organization money
   - A palliative care program could increase the organization's capacity to earn revenues

20. Please indicate which of the following best describes your desire to learn about best practices in palliative care?
   - Very interested
   - Somewhat interested
   - Not interested
21. Please indicate your top organizations top three goals for the new year, as they relate to palliative care. (Please leave them blank, if this is not applicable to your organizations).
   1. __________________________
   2. __________________________
   3. __________________________

22. Please list the term that you feel best describes the type of healthcare organization which your organization is in the box below:

23. Please indicate your organization’s approximate annual budget:
   • $_______

24. Are there other ideas/issues that you would like to note here? If yes, please list them in the box below:
Appendix D

Foundation Survey

1. Which of the following best describes your knowledge about palliative care?
   - I have a comprehensive understanding of the subject.
   - I have a great deal of knowledge about the subject.
   - I know some things about the subject.
   - I know very little about the subject.
   - I know nothing about it.

2. Which of the following best describes your understanding of the difference between hospice and palliative care as they are currently used in healthcare and philanthropy?
   - The difference between the terms is very clear to me.
   - I have some understanding of the difference.
   - I see them as related, but separate.
   - I have no idea what the difference is.

3. Which of the following best describes your understanding of recent palliative care work in the U.S.?
   - I know a great deal about what has been done in this category.
   - I know that some work has been done.
   - It sounds familiar, but I don’t really know much about it.
   - I have heard nothing about it.

4. Of the following, which best describes any grantmaking that your foundation does (or would do) that is related to palliative care work?
   - The Foundation has a grantmaking focus in this category.
   - The Foundation has conducted some work in this category.
   - The Foundation will explore work in this category in the future.
   - The Foundation might explore work in this category in the future.
   - The Foundation is unlikely to pursue work in this category.
   - Other, please specify ________________________________

5. Please check any of the following that represent types of palliative care or end-of-life grantmaking that your foundation is currently doing or has done in the past (Please check all that apply):
   - Advanced Directives
   - Advocacy/Awareness
   - Bereavement Services
   - Collaborations
   - Conferences

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6. Please check all of the following your foundation would be most likely to support, if it were to work in palliative care?

- Advocacy/Awareness
- Bereavement Services
- Collaborations
- Conferences
- Demonstration or Pilot Programs
- Direct Services
- Dissemination
- Ethics
- Family Caregiving
- Fellowships
- Hospice
- Leadership Training
- Legal Issues
- Nursing Homes
- Operating Support
- Palliative Care
- Policy
- Professional Education
- Program Evaluation
- Program Replication
- Public Policy
- Religion
- Research Rural Issues
- Spirituality
- Support of the Arts related to chronic illness or death
- Symptom Management
- Technical Assistance
- Therapies (massage, music, etc.)
- Training and Education
- Volunteers
- Other, please specify ________________________
7. Please indicate which of the following best describes your desire to learn about possibilities for palliative care grantmaking:
   - Very interested
   - Somewhat interested
   - Not interested

8. If palliative care grantmaking were a priority for the grantmaking organization for which you work, which of the following factors would influence decision-making? (Please check all that apply.):
   - Increase recognition of palliative care options as a pressing societal and personal concern of families
   - Foundation's pre-established priorities
   - Assessment of need in the community
   - Opportunity to make a visible difference
   - Opportunity to capitalize on funding models that have proven to be effective
   - Personal interest of the Board
   - Personal interest of Staff
   - Incoming proposal requests
   - Opportunity for collaboration with other grantmakers
   - Opportunity to inform public policy initiatives
   - Opportunity to fill gaps in knowledge
   - Opportunity for public-private collaboration
   - Opportunity to test innovations
   - Current events in the media and Congress
9. Please indicate your top three healthcare grantmaking priorities in the spaces below:
   1. __________________________
   2. __________________________
   3. __________________________

10. Please indicate which of the following best describes your grantmaking organization:
    1. Corporate foundation
    2. Family foundation
    3. Independent foundation
    4. Operating Foundation
    5. Public Charity
    6. Other. Please specify.

11. Please indicate your Foundation’s current asset value:
    • $_______

12. Please estimate the total number of grant awards made during the current year and estimate the total value of the total grants to be awarded.
    • Total number of grants: _______
    • Total value of all grants: $_______

13. Please indicate the number of palliative care grants made this year:
    • Total number of palliative care Grants: _______
    • Total value of all grants: $_______

14. Please indicate the number of end-of-life care/ hospice grants made this year:
    • Total number of end-of-life/hospice grants: _______
    • Total value of all grants: $_______

15. Which of the following best describes the geographic focus of your foundation’s work:
    • Local
    • Regional
    • County-wide
    • State-wide
    • National
    • International

16. Are there other ideas/issues that you would like to note here? If yes, please list them in the box below:
Appendix E

*Palliative Care Expert Interview Guide*

1. What items are at the top of the agenda for the palliative care field?

2. What is the focus of your/your organization’s work and where does it fall in this agenda?

3. What are the major gaps in palliative care delivery from your perspective?

4. What is being done about the gaps?

5. If it were your job to distribute grant funds for palliative care across one region (e.g., the San Francisco Bay Area), how would you prioritize?

6. If you were charged with distributing multi-million dollar grants for palliative care across one region (e.g., the San Francisco Bay Area), what would your priorities be?

7. If money were no object what would you do at your organization in the area of palliative care?

8. What are the best models of palliative care work that you know of in the U.S.?

9. Are you aware of any in the Bay Area?

10. What are the best practices that you are aware of?

11. What hasn’t worked?

12. What has changed since you’ve been working in the field?

13. What capacity does the field have for measuring its impact?

14. Who are the leaders in the field?

15. What is your vision for palliative care delivery?
Appendix F

Healthcare Organization Survey Introduction Letter

Date

Name, Title
Organization
Address
City, CA 11111

Dear Name:

My name is Ned Schaub and I am a graduate student in the College of Professional Studies at the University of San Francisco. I am conducting a study to identify interest in and opportunities for palliative care funding in the San Francisco Bay Area. I am working to identify general funder interest and existing plans or efforts. I am also working to identify the needs of Bay Area healthcare organizations that are currently considering expansion or redefinition of their palliative care services program(s); and to identify the needs of those that do not currently have a palliative care services program, but that hope to implement one in the future.

I am writing to you to request your participation in an online survey that should not take more than 10 to 15 minutes to complete. Organization Name has been identified as a hospital (Note: One of the following would be indicated here depending on the type of organization: home healthcare agency, nursing home or hospice) in County Name County. I will follow this letter with an email to you in the next week. If you agree to participate in the survey, you will be able to initiate it by double-clicking on a link that will be available in the text of the email.

While there will be no immediate benefit to you from participating in the survey, the anticipated benefit is a better understanding of the possibilities for the expansion and implementation of palliative care work in the Bay Area. The results of the survey will be used for my master’s thesis and will be made available to you, and to other interested parties, including healthcare organizations and healthcare funders. In addition to my graduate studies, I am currently working with the grantmaking affinity group, Grantmakers in Aging, in developing a palliative care component for their “funder’s toolkit.” I hope that the results of the survey will contribute to the efforts of Grantmakers in Aging and funders who are considering work in palliative care.

Participation in this research is voluntary. Should you decide to participate in the survey, you are free to decline to answer any questions you do not wish to answer, or to stop participation at any time. No individual or organization identities or results will be used in any reports or publications resulting from the survey. Every effort will be made to maintain confidentiality. Data from the survey will be coded and kept in locked files at all times and only I will have access to the files. There will be no costs to you as a result of taking part in the survey, nor will you be reimbursed for your participation.
If you have questions about the survey or my research, you may contact me at (415) 864-3869. If you have further questions, you may contact the University of San Francisco’s Internal Review Board for the Protection of Human Subjects by e-mailing IRBPHS@usfca.edu, or by calling (415) 422-6091 and leaving a voicemail message.

Many thanks for your attention.

Sincerely,

Edward “Ned” Schaub, Graduate Student
University of San Francisco
Dear Name:

My name is Ned Schaub and I am a graduate student in the College of Professional Studies at the University of San Francisco. I am conducting a study to identify interest in and opportunities for palliative care funding in the San Francisco Bay Area. I am working to identify general funder interest and existing plans or efforts. I am also working to identify the needs of Bay Area healthcare organizations that are currently considering expansion or redefinition of their palliative care services program(s); and to identify the needs of those that do not currently have a palliative care services program, but that hope to implement one in the future.

I am writing to you to request your participation in an online survey that should not take more than 10 to 15 minutes to complete. I have identified Foundation Name as a Bay Area healthcare funder, through my preliminary research at the San Francisco Foundation Center. I will follow this letter with an email to you in the next week. If you agree to participate in the survey, you will be able to initiate it by double-clicking on a link that will be available in the text of the email.

While there will be no immediate benefit to you from participating in the survey, the anticipated benefit is a better understanding of the possibilities for the expansion and implementation of palliative care work in the Bay Area; and for potential local foundation support. The results of the survey will be used for my master's thesis and will be made available to you, and to other interested parties, including healthcare organizations and healthcare funders. In addition to my graduate studies, I am currently working with the grantmaking affinity group, Grantmakers in Aging, in developing a palliative care component for their “funder’s toolkit.” I hope that the results of the survey will contribute to the efforts of Grantmakers in Aging and funders who are considering work in palliative care.

Participation in this research is voluntary. Should you decide to participate in the survey, you are free to decline to answer any questions you do not wish to answer, or to stop participation at any time. No individual or organization identities or results will be used in any reports or publications resulting from the survey. Every effort will be made to maintain confidentiality. Data from the survey will be coded and kept in locked files at all times and only I will have access to the files. There will be no costs to you as a result of taking part in the survey, nor will you be reimbursed for your participation.
If you have questions about the survey or my research, you may contact me at (415) 864-3869. If you have further questions, you may contact the University of San Francisco’s Internal Review Board for the Protection of Human Subjects by e-mailing IRBPHS@usfca.edu, or by calling (415) 422-6091 and leaving a voicemail message.

Many thanks for your attention.

Sincerely,

Edward “Ned” Schaub
Graduate Student
University of San Francisco
Appendix H

_Palliative Care Expert Recruitment Email_

Dear Name:

My name is Ned Schaub and I am a graduate student in the College of Professional Studies at the University of San Francisco. As a part of my master’s thesis research I am conducting a study to identify interest in and opportunities for palliative care funding in the San Francisco Bay Area. I am working to identify general funder interest and existing plans or efforts. I am also working to identify the needs of Bay Area healthcare organizations that are currently considering expansion or redefinition of their palliative care services program(s); and to identify the needs of those that do not currently have a palliative care services program, but that hope to implement one in the future. I have identified you as a key expert source in the course of my initial thesis research, or through my professional work as a grantmaker in the field(s) of aging and/or end of life. I am writing to you now to request a brief interview with you as a part of my primary research.

While there will be no immediate benefit to you from participating in the interview, the anticipated benefit is a better understanding of the possibilities for the expansion and implementation of palliative care work in the Bay Area. The results of my research will be used for my master’s thesis and will be made available to you, and to other interested parties, including healthcare organizations and healthcare funders. In addition to my graduate studies, I am currently working with the grantmaking affinity group, Grantmakers in Aging, in developing a palliative care component for their “funder’s toolkit.” I hope that the results of the survey will contribute to the efforts of Grantmakers in Aging and funders who are considering work in palliative care. There will be no costs to you as a result of taking part in this interview, nor will you be reimbursed for your participation in this study.

Participation in this research is voluntary. Should you decide to participate in the interview, you are free to decline to answer any questions you do not wish to answer, or to stop participation at any time. No individual or organization identities or results will be used in any reports or publications resulting from the survey. Every effort will be made to maintain confidentiality. Data from the survey will be coded and kept in locked files at all times and only I will have access to the files. There will be no costs to you as a result of taking part in the survey, nor will you be reimbursed for your participation.

If you have questions about the survey or my research, you may contact me at (415) 864-3869. If you have further questions, you may contact the University of San Francisco’s Internal Review Board for the Protection of Human Subjects by e-mailing IRBPHS@usfca.edu, or by calling (415) 422-6091 and leaving a voicemail message.

At your convenience, please let me know if you would be available for a 20 to 30 minute interview. You may reach me by email (ejschaub@usfca.edu) or by phone (415-864-3869).

Many thanks for your attention.

Ned Schaub, Graduate Student, University of San Francisco

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Appendix I

Healthcare Organization Survey Email Text

Dear Name:

I sent a letter to you about a week ago to request your participation in an online survey. As I mentioned in the letter, I’m a graduate student working on my master’s thesis in the Master of Nonprofit Administration Program in the College of Professional Studies at the University of San Francisco. I am conducting a study to identify interest in and opportunities for palliative care work and related funding opportunities in the San Francisco Bay Area. Name of Organization has been identified as a hospital (Note: One of the following would be indicated here depending on the type of organization: home healthcare agency, nursing home or hospice) in Name of County.

If you agree to participate in the survey, which should not take more than ten to fifteen minutes, you will be able to initiate it by double-clicking on the link below. While there will be no immediate benefit to you from participating in the survey, the anticipated benefit is a better understanding of the possibilities for the expansion and implementation of palliative care work in the Bay Area. The results of the survey will be used for my master’s thesis and an executive summary of it will be available to you, and to other interested parties, including healthcare organizations and healthcare funders.

Participation in this research is voluntary. Should you decide to participate in the survey, you are free to decline to answer any questions you do not wish to answer, or to stop participation at any time. No individual or organization identities or results will be used in any reports or publications resulting from the survey. Every effort will be made to maintain confidentiality. Data from the survey will be coded and kept in locked files at all times and only I will have access to the files. There will be no costs to you as a result of taking part in the survey, nor will you be reimbursed for your participation. If you have questions about the survey or my research, you may contact me at (415) 864-3869. If you have further questions, you may contact the University of San Francisco’s Internal Review Board for the Protection of Human Subjects by e-mailing IRBPHS@usfca.edu, or by calling (415) 422-6091 and leaving a voicemail message.

Bay Area Palliative Care Survey: www.surveyorg.com/bayareapalliativecaresurvey

Thank you for your attention.

Ned Schaub
Graduate Student, University of San Francisco
Appendix J

Foundation Survey Email Text

Dear Name:

I sent a letter to you about a week ago to request your participation in an online survey. As I mentioned in the letter, I’m a graduate student working on my master’s thesis in the Master of Nonprofit Administration Program in the College of Professional Studies at the University of San Francisco. I am conducting a study to identify interest in and opportunities for palliative care work and related funding opportunities in the San Francisco Bay Area. Foundation Name has been identified as a Bay Area funder.

If you agree to participate in the survey, which should not take more than 10 to 15 minutes, you will be able to initiate it by double-clicking on the link below. While there will be no immediate benefit to you from participating in the survey, the anticipated benefit is a better understanding of the possibilities for the expansion and implementation of palliative care work in the Bay Area. The results of the survey will be used for my master’s thesis and an executive summary of it will be available to you, and to other interested parties, including healthcare organizations and healthcare funders.

Participation in this research is voluntary. Should you decide to participate in the survey, you are free to decline to answer any questions you do not wish to answer, or to stop participation at any time. No individual or organization identities or results will be used in any reports or publications resulting from the survey. Every effort will be made to maintain confidentiality. Data from the survey will be coded and kept in locked files at all times and only I will have access to the files. There will be no costs to you as a result of taking part in the survey, nor will you be reimbursed for your participation. If you have questions about the survey or my research, you may contact me at (415) 864-3869. If you have further questions, you may contact the University of San Francisco’s Internal Review Board for the Protection of Human Subjects by e-mailing IRBPHS@usfca.edu, or by calling (415) 422-6091 and leaving a voicemail message.

Bay Area Palliative Care Survey:
www.surveyorg.com/bayareapalliativecaresurvey (Please note that this is currently a false internet link, but would be replaced with an actual one.)

Thank you for your attention.

Ned Schaub
Graduate Student, University of San Francisco
Appendix K

Palliative Care Expert Verbal Consent Script

Hello. My name is Ned Schaub, and I'm a graduate student working on my master's thesis in the Master of Nonprofit Administration Program in the College of Professional Studies at the University of San Francisco. I have identified you as a key expert source in the course of my initial thesis research, or through my professional work as a grantmaker in the field of aging or end of life. I would like to interview you as a part of my primary research. To comply with University rules, I must now give you a brief explanation of the study and get your consent to participate.

You are being asked to participate in my research because I have identified you as a key expert source with essential expertise and information for the development of my thesis. I have identified you as a funder, provider, or other expert in the field of palliative care. Please feel free to decline to answer any question that you do not feel comfortable with, do not have an opinion on, or which you simply do not wish to answer. Please also feel free to stop participation at any time. Every effort will be made to keep records of the interview confidential. No individual or organization identities will be used in any reports or presentations. Interview information and comments will be kept in my home office, in a locked filing cabinet and/or in a secure computer data base at all times. Only I will have access to the cabinet and computer data base. Individual information and results will not be shared with others.

While there will be no immediate benefit to you from participating in the survey, the anticipated benefit is a better understanding of the possibilities for the expansion and implementation of palliative care work in the Bay Area. The results of the survey will be used for my master's thesis and will be made available to you, and to others who are interested, including healthcare organizations and healthcare funders. Over the last eight years I have worked in professional philanthropy, and continue to work with philanthropists working in the fields of aging and end-of-life. So, in addition to my graduate studies I am currently working with the grantmaking affinity group, Grantmakers in Aging, in developing a palliative care component for their "funder's toolkit." I hope that the results of the research will contribute to the efforts of Grantmakers in Aging and funders who are considering work in palliative care. There will be no costs to you as a result of taking part in this interview, nor will you be reimbursed for your participation in this interview.

If you have questions about the interview in the future, you may contact me by email at ejschaub@usfca.edu or by telephone at (415) 864-3869. You may also contact the University of San Francisco's Internal Review Board for the Protection of Human Subjects by email at IRBPHS@usfca.edu, or by calling (415) 422-6091 and leaving a voicemail message.

Once again, participation in this interview is voluntary. You are free to decline to be a part of my research, or to withdraw from the interview at any point.

If you agree to participate, please say so now. Many thanks.
Copyediting Approval

Master of Nonprofit Administration
College of Professional Studies
University of San Francisco

The thesis *Quality of Life for Patients and Caregivers: Palliative Care Funding Opportunities* by Edward Joseph Schaub has been reviewed and is given copyediting approval by

_Daniel Ashby_
Copy editor, Daniel Ashby

_June 6, 2017_
Date