

Creating an Academic-Community Provider Partnership in Hospice, Palliative Care, and End-of-Life Studies

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Introduction

Improving care in the final phase of life has been an important medical and societal goal during the last two decades. The field of palliative care has been moved forward by thoughtful and rigorous research that seeks to clarify the values and treatment preferences of people in the last phases of their lives and of their families, determines effective methods to control pain and other symptoms, and improves access to quality end-of-life care. Conducting research with dying patients in palliative care settings can be challenging, and such studies can be methodologically complex.¹⁻⁴ Palliative care participants in research studies are often available for only short periods of time; they may die or become incapacitated before data can be collected. Studies are often designed so that patient information is gathered on admission to a hospice or palliative care setting, yet this may be a time of crisis when data collection is inappropriate and unwelcome. The knowledge that time together for the patient and family is limited may also mean that they wish to focus on activities of closure rather than participate in research.

In response to the need for research that best fits end-of-life care situations and settings, a collaborative research center was established to further end-of-life studies by the University of South Florida (USF) and key community partners, including The Hospice of the Florida Suncoast,

LifePath Hospice and Palliative Care, Inc, Hope Hospice and Palliative Care, Hospice of Southwest Florida, and the H. Lee Moffitt Cancer Center & Research Institute. The Center for Hospice, Palliative Care and End-of-Life Studies at USF connects academic research and clinical expertise with community provider research and clinical expertise to jointly focus on research questions pertinent to current and future practice, systems of care, and public policy. The University affiliation provides credibility, offers access to the broad resources of the campus, and attracts top researchers, while community providers have access to not only patients and families, but also to much-needed practical advice about how such studies can be designed and conducted to maximize benefits to patients, families, and care providers.

Background

The Center for Hospice, Palliative Care and End-of-Life Studies at USF began informally in 1996 when an interdisciplinary research group on the USF campus was joined by faculty and hospice staff from LifePath Hospice and Palliative Care, Inc, who had been meeting to identify valid and reliable instruments that would be useful in hospice settings. The Center, which was formally recognized by USF in 2000, brought together administrators, researchers, and clinicians from six hospices across West Central Florida, including the two largest not-for-profit hospices in the country — The Hospice of the Florida Suncoast, and LifePath Hospice and Palliative Care, Inc — as well as the H. Lee Moffitt Cancer Center & Research Institute, the James A. Haley Veterans Hospital, and faculty from the USF Colleges of Medicine, Nursing, Public Health, and Arts and Sciences.

The field of hospice and palliative medicine has grown tremendously over the past 20 years. According to last year's survey by the National Hospice and Palliative Care Organization, the number of hospice programs has more than doubled, from 1,545 programs in 1985 to more than 3,200 today.⁵ Even more impressive is the nearly 6-fold growth in the number of patients served, from an estimated 158,000 in 1985 to more than 885,000 in 2002. This growth in clinical capacity has been aided by growth in research on end-of-life issues. Unlike research in cancer, for example, where both patients/subjects and academi-

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cally trained physician researchers coexist to facilitate the development and completion of clinical trials, most hospice patients are cared for by small, community-based provider agencies that lack a research infrastructure. In the Tampa area, however, The Hospice of the Florida Suncoast and LifePath Hospice and Palliative Care, Inc, have not only large patient populations, but also developed research capabilities. The formal partnership created by the Center for Hospice, Palliative Care and End-of-Life Studies at USF recognized that the credibility and access to research funding of the University, combined with the patient populations and clinical and research capacity of these local hospice organizations, could make a significant contribution to research on end-of-life care. In addition, the Center links smaller hospice organizations in the Tampa region that are interested in research but lack the expertise to conduct rigorous studies.

The University faculty brings expertise in research, and the community providers bring real-world expertise that facilitates the completion of projects. For example, prior to the collaboration of the University and community provider partners, studies were routinely proposed that required a baseline assessment of hospice patients. However, admission to hospice is difficult enough for patients and families without introducing additional scales or research protocols. In addition, research findings can be immediately implemented in community provider agencies, which improves the care patients receive. The collaboration of Center members in the early development of research ideas, study design, and dissemination of outcomes not only reduces the problems that can derail research in this vulnerable population, but also aids in the dissemination of research findings.

The transition from an interdisciplinary research interest group to a Center that is formally recognized by the University required the persistent belief that research and educational efforts aimed at improving end-of-life care were important and would best be achieved through collaborative partnership. Such collaborative arrangements with the University were new territory, as the model had been that community organizations were encouraged to donate funds to the University but not have a role in disbursement decisions. University administration unfamiliar with the requirements of end-of-life research needed to be educated about the growing expertise that University faculty were developing in this emerging area, as well as an understanding of what more could be accomplished through the development of an organized research center.

By becoming convincing advocates for patients and families, for academic/community provider partnerships, and for end-of-life scholarship, the Center eventually won the recognition and financial support of the University. It also attained the financial support of founding partners LifePath Hospice and Palliative Care, Inc, and The Hospice of the Florida Suncoast, as well as financial sponsorship from the H. Lee Moffitt Cancer Center & Research Insti-

tute. Pledges from USF and the Center's community sponsoring organizations ranging from \$50,000 to \$100,000 provided initial and ongoing funding for the Center. These community sponsors have recently been joined by Hope Hospice and Palliative Care and Hospice of Southwest Florida, both of which have also pledged financial support to the Center and have joined in the executive leadership and oversight of Center projects.

The Center for Hospice, Palliative Care and End-of-Life Studies at USF is an organized research center in the Health Sciences Center. Other centers nationwide devoted to end-of-life research are either freestanding (such as the Midwest Center for Bioethics) or affiliated with hospice organizations (such as The Hospice Institute of the Florida Suncoast) or with universities. Each of these organizational structures has advantages and disadvantages. University-affiliated centers generally cite credibility, university resources, and ability to attract researchers as advantages, and bureaucracy, high overhead costs, and competing demands as disadvantages.

Organizational Structure

The Center's organizational structure (Figure) reflects an academic/community provider partnership. The Center is co-directed by an Academic Director, who oversees University faculty associated with the Center, and a Community Director, who manages the Center's relationships with partner community providers and potential partners. The Center is an integrated partnership between community organizations and USF in terms of governance, financial support, and the establishment of priorities and goals. The Center is governed by an Executive Committee that represents both the academic and community provider partners and is governed by a set of bylaws recently ratified by members of the Center's Executive Committee and the academic leaders of USF's Health Sciences Center. The Center bylaws were drafted by the Executive Committee leadership of the Center, a lengthy process that required understanding of the point of view, systems, and culture of the academic environment by community partners and also of providers' systems and culture by University partners.

Center membership is open to any individual interested in end-of-life care and research. Current members include faculty members and students from several colleges, disciplines, departments and schools, as well as administrators, clinicians, research directors and medical directors of area hospices, and physicians, clergy, nurses, and social workers from multiple hospices and hospitals in the Tampa area. Center members participate in monthly meetings during which original research is presented, can compete for pilot research grant funding offered by the Center, and have a regular forum for networking and sharing research ideas, problems, and opportunities.

The mission of the Center is to optimize care and systems of care for patients faced with advanced noncurable diseases and their families by generating new knowledge through interdisciplinary research, using that knowledge to educate health and human services professionals, and influencing public policy that supports quality end-of-life care. Areas of research that have been addressed by Center members include quality of life issues, symptom management, caregiver issues, and access to hospice care.

The Center is able to develop and conduct research projects in these and other emerging priorities in end-of-life and palliative care as a result of direct collaborations between researchers and clinicians who are providing the “hands-on” care to patients near the end of life and their families. The strength of the Center lies in its ability to influence and improve end-of-life care through its research and educational endeavors. Because research questions investigated by the Center have largely emerged from those involved in direct patient care, the research undertaken by Center partners is salient to public policy as well as the establishment of best practices in end-of-life care.

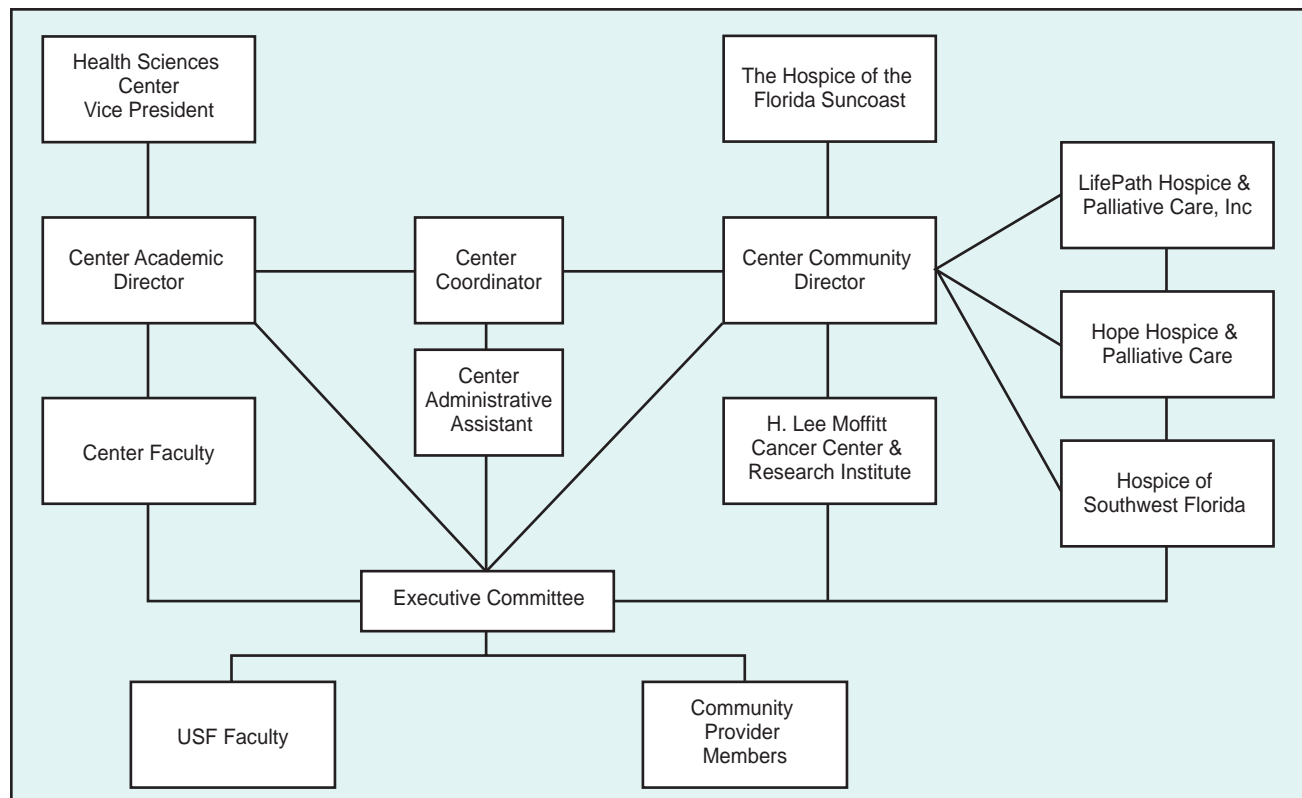
The Center began with a core group of researchers who had successfully collaborated on past projects on palliative and end-of-life care that led to large, federally funded projects. It brings the research and funding expertise of these senior members to the group at large, by both sharing the development and progress of their projects and offering critiques of research studies proposed by less experienced members. Currently, the Center Executive

Committee members are working to develop a model for projects that emerge from the collaboration and can be clearly identified as “Center” projects. A white paper that explores barriers to hospice and end-of-life care developed for the Agency for Healthcare Research and Quality following the Center’s last educational symposium is providing a roadmap for new projects to be developed by Center members.⁶

Research Goals

The Center for Hospice, Palliative Care and End-of-Life Studies at USF addresses the need for interdisciplinary research through University/community provider collaboration aimed at improving end-of-life care experiences for patients and their families, systems of care, and public policy to support care. It has developed a model for conducting rigorous research with a vulnerable patient population on issues that may be ethically challenging, and it has a track record of publications, presentations, and grant funding for projects and conferences that are helping to define the field of end-of-life studies.

Each year, the Center funds several pilot research grants of up to \$5,000 each to encourage junior faculty, graduate students, and community provider staff members to explore research topics in end-of-life care and provide start-up funds for established researchers to collect pilot data on new areas of investigation. To date, nearly \$23,000



Organizational structure of the University of South Florida Center for Hospice, Palliative Care and End-of-Life Studies.

in pilot research grant funding has been awarded to investigate issues that include guided imagery for hospice patients with dyspnea, hospice volunteers, Korean-Americans' preferences for end-of-life care, telenursing, and chemotherapy use among hospice cancer patients.

The Center also offers graduate research assistantships for 1 to 2 doctoral students each year who are completing doctoral degrees in fields such as nursing, aging studies, gerontology, and communication and who are conducting research on end-of-life issues. Graduate students are integrated into the work settings of the care providers, and their research projects are designed to meet a current need of provider agencies. Findings and conclusions are provided to agency staff members as well as at Center meetings. Nearly \$24,000 in research assistantship funding was awarded to support doctoral students at USF conducting dissertation research on end-of-life issues. Pilot grants and research assistantship funding encourage doctoral students, junior faculty, and more senior faculty new to end-of-life research and staff members of community provider agencies to develop projects focusing on improving end-of-life care.

The Center's Executive Committee members, several of whom have experience with Institutional Review Boards (IRBs) as well as extramural funding agencies, provide free consultations to Center members preparing grant proposals and IRB applications. This expert review is especially important when approaching IRB committees with end-of-life research proposals, since most are unfamiliar that research can and should include dying patients and their families as long as appropriate safeguards are in place.

Center members have a strong track record of obtaining funding for research as well as publishing results of studies that lead to improved care for both enrolled and nonenrolled study participants, as well as patients and families enrolled or not enrolled in hospice programs, near the end-of-life. Patient care problems and issues have been identified, interventions have been developed and evaluated, and validated instruments have been incorporated in some of the member hospice organizations to objectively monitor symptoms such as pain, dyspnea, falls, fatigue, depression, and quality of life. Center members disseminate their research findings by publishing in peer-reviewed journals and lay publications, by participating in in-services and other educational and training programs and conferences, and by implementing protocols and assessment instruments in the clinical settings in which they work. In addition, research conducted by Center members helps to improve the ability of other researchers to conduct studies on end-of-life issues by providing models and methods that effectively recognize the differences inherent in conducting research with patients near the end of life.

Recognizing the special nature of the end-of-life experience, partners in the Center strive to honor the pre-

sciousness of time at the end of life by reducing research demands placed on patients and their families. Researchers associated with the Center are sensitive to the relationship between hospice staff and their patients and families, and every effort is made to allow patients and families the choice of not participating in research. The use of IRB-approved protocols with their informed consent features serve as cornerstones in the Center's efforts to ensure that patients and their families feel no obligation to participate in their hospice's research. The data collection burden on participating patients and families, as well as on clinical staff members, is kept to a minimum. Hospice staff members meet regularly with researchers as studies are being designed to collaborate on study design and data collection methods that are likely to be feasible within the existing systems of care.

The effectiveness of the Center members' ability to translate research findings into practical improvements in patient care is tracked. For example, changes in practice in pain management have occurred as a result of early studies conducted by Center members that revealed improvement in patients' pain ratings.⁷⁻⁹ Access to hospice care has been improved by utilizing the results of studies conducted by Center members investigating prognosis in patients with advanced disease and evaluation of Medicare's local medical review policies.^{10,11}

The research expertise and collaboration between Center members has led to projects in a number of areas, particularly patient and family well-being and quality of life, support for surrogates and agents, comprehensive caring and continuity of care, and caregiver concerns. Each of these areas is described in the following sections.

Patient and Family Well-Being and Quality of Life

Respect for the multidimensional components of patient well-being and quality of life motivates much of the research conducted by Center members. The development of measures, protocols, and programs that enhance the well-being of patients and their families and improve the quality of end-of-life care is the focus of many projects undertaken by members of the Center to address depression at the end of life, quality of life applicable to hospice settings, pain, fatigue, and falls.

Center members received support from the National Cancer Institute to determine the incidence, prevalence, and course over time of depressive symptomatology in lung cancer patients.¹² Another study sought to increase clinicians' awareness of screening and appropriate assessment of clinical depression in home hospice cancer patients.¹³ The Hospice Quality of Life Index was also developed and its reliability and validity confirmed.¹⁴⁻¹⁶ A large intervention study funded by Health Services Research and Development of the Veterans Administration

included assessment of pain intensity using the Brief Pain Inventory in veterans with cancer who had been admitted to the hospital for at least 48 hours.⁷

Support for Surrogates and Agents

Surrogate decision-makers has also been the research target of Center members, including studies that investigate the decision to enter hospice, evaluate changing preferences for cardiopulmonary resuscitation (CPR) in elderly patients, and describe cross-cultural variation in the use of advance directives.

One study identified the factors that impact the decision of whether to enter a hospice program or continue with a traditional curative approach to care in cancer patients with limited life expectancies.¹⁷ The results of this study revealed the multiplicity of factors that affect the decision to enter hospice and may result in increased access to hospice care for those in need of such services.

A series of studies that explored preferences for CPR revealed that most elderly patients desire discussion about end-of-life decision-making, that CPR preferences in an elderly population can change as a result of educational interventions, that there is a strong relationship between socioeconomic status and desire for CPR, and that life values have a strong relationship to treatment preferences among elderly patients.¹⁸⁻²¹

Comprehensive Caring and Continuity of Care

Critical components of quality end-of-life care include caring for patients and families as the setting of care changes, maximizing the function and comfort of patients, and assisting with life closure for patients and bereavement for families. Most of the work of the Center with regard to comprehensive caring and continuity of care has involved working with skilled nursing facilities and assisted living facilities in order to develop the capacity to provide quality end-of-life and palliative care. Center members include the medical directors of several nursing homes and assisted living facilities in the Tampa area, which is home to over half the skilled nursing facilities in Florida. The James A. Haley Veterans Hospital, located in close proximity to USF, has an inpatient hospice unit with dedicated beds in its skilled nursing facility for palliative care. The physicians who manage these services are members of the Center.

Center members have studied the need for hospice in long-term care environments,²² have investigated the importance of quality of life across all settings,²³ and are currently completing a pilot study on the perceptions of nursing professionals in long-term care facilities about their ability to influence the quality of life of residents near the end of life.²⁴

Caregiver Concerns

Another strength of Center members is conducting research that addresses caregiver concerns. For example, The Hospice of the Florida Suncoast, one of the founding partners of the Center, has received support to conduct the first national needs assessment of family caregiver needs at the end of life, as well as design a national train-the-trainer program for professionals. The goal of the program is to provide caregivers with the information and tools to focus on meaningful relationships and life closure with the care receiver.

Studies supported by the National Cancer Institute included evaluation of caregiver intervention to improve hospice outcomes and a study to investigate the stress associated with cancer caregiving.²⁵ Another project developed skill training interventions for African-American and white caregivers, as well as the racial and longitudinal effects of caregiving in Alzheimer's disease.²⁶

Educational Outreach

The Center develops and sponsors educational programs about end-of-life care. For the past 8 years, a 16-hour medical student rotation in hospice and end-of-life care has been a required portion of the Internal Medicine clerkship at USF for all third-year medical students. Approximately 800 medical students have completed this rotation to date.²⁷⁻²⁹ Initially funded by a National Cancer Institute grant, this program has successfully continued with the support of LifePath Hospice and Palliative Care, Inc, a founding partner of the Center. Physicians who completed their hospice rotation during medical school 5 years earlier have reported that the care they provide to patients near the end of life was positively affected.³⁰

The hospice provider agencies also collaborate to support hundreds of interdisciplinary student clinical affiliations that vary from a few days of observation to full semesters of learning and internships. For instance, The Hospice of the Florida Suncoast hosts over 425 nursing, social work, chaplaincy, pharmacy, gerontology, and psychology students annually to provide first-hand learning experiences with patients, families, and interdisciplinary team members.

An interdisciplinary Graduate Certificate Program in Palliative Care and End-of-Life Studies has recently been approved through the efforts of the Center, and certificate courses are offered at USF every semester. This certificate program provides advanced training for graduate students and health professionals in palliative and end-of-life care, and it prepares its graduates to provide state-of-the-art care to patients near the end of life and their families.

The Center has also sponsored, with external support, a number of research and educational symposia that have attracted the participation of researchers, hospice

and hospital administrators, nurses, social workers, physicians, chaplains, attorneys, and legislators from around the country.

Policy and Advocacy

Shaping local, regional, and national public policy related to end-of-life care is central to the mission of the Center. Research and advocacy are two of the main levers that shape policy; thus, the generation and dissemination of high-quality research are essential to create the data on which policy decisions are based. Center members present an average of 25 research presentations each year at regional, state, and national meetings, including the American Academy of Hospice and Palliative Medicine, the National Hospice and Palliative Care Organization, American Society on Aging, the Gerontological Society of America, the National Association of Elder Law Attorneys, and the Guardianship Association. The topics covered are varied, including wound palliation, innovative approaches to non-pain symptom management, Hispanic families and hospice care, improvement in access to hospice and end-of-life care, governance in hospice organizations, caregiver support systems, and spiritual pathways through dementia.

Maximizing access to hospice care for those in need, as well as for those desiring hospice services, has been a focus of concern by members of the Center. Research projects have helped to estimate the likely prognosis for patients with many diagnoses near the end of life,^{10,31} and one study reported factors used in the decision to enter hospice or continue with traditional hospital care for patients with advanced malignancies.¹⁷

Conclusions

The Center for Hospice, Palliative Care and End-of-Life Studies at USF is an interdisciplinary research center that emphasizes improving experiences of patients and families through University/community provider engagement, promotes leadership that represents the interests of many disciplines and organizations, and has a policy of inclusive membership. Although interdisciplinary research and collaboration and University/community engagement are popular concepts and goals, they are challenging to achieve in practice. The Center has developed a model where contributions — whether of time, leadership, money, or scholarship — are valued from many disciplines and from many organizations.

The strength of the Center lies in its ability to influence and improve end-of-life care through its interdisciplinary and collaborative research and educational endeavors. Because research questions investigated by the Center have largely emerged from the field, the research undertaken by Center partners is salient to current prac-

tice and public policy and ultimately has the potential to change policy and systems of care in purposeful ways. The Center's most significant accomplishments to date include the following:

- over \$11,750,000 in funded research to investigators affiliated with the Center, particularly in the multidimensional components of patient well-being and quality-of-life, and caregiver concerns
- dissemination of research results in peer-reviewed journals and research conferences
- outcomes from research projects and educational endeavors that have improved practices and care for patients near the end of life and their families
- interdisciplinary scholarship and leadership
- the Graduate Certificate Program in Palliative Care and End-of-Life Studies
- mechanisms that permit interested graduate students and faculty to pursue research on end-of-life issues including Graduate Research Assistantships, a Pilot Research Grant Program, and a competitive research award as part of our annual symposia
- educational programs including the 16-hour medical student rotation in hospice and end-of-life care, research symposia that feature internationally known scholars and clinicians, and the integration of hundreds of students from a variety of disciplines into hospice and palliative care rotations
- integration of current provider practitioners into academic settings and academic professionals into clinical settings, thus creating an ongoing, dynamic partnership that is visible in practice
- recognition of the unique expertise each partner brings with increasing openness to learn and understand what drives each culture

The Center for Hospice, Palliative Care, and End-of-Life Studies began with an interdisciplinary core group of researchers who successfully collaborated on a series of federally funded research projects. This core group of investigators could have continued their program of research without dedicating the time, effort, and energy needed to create an organized research center and University/community provider partnership. The expertise, enthusiasm, and success of this core group has led to the creation of an organized research center, which in turn encourages students and junior faculty to specialize in end-of-life studies, brings awareness to the academic and provider communities of USF's growing reputation in this area, effectively utilizes the expertise and hospice patient populations of our community partner hospices, and facilitates collaboration with other hospices in our region.

Keys to the Center's early success included seeking partnerships and collaborative relationships with diverse organizations, establishing a clear mission, keeping track of accomplishments, and establishing regular meetings with clear agendas. Above all, researchers and providers in the challenging field of end-of-life and palliative care must

continue to focus on the value of their work in influencing the experiences of patients, families, and communities.

The Center has been fortunate to have not only skilled researchers but also community partners who have strong administrative and research experience and who provided financial support to begin the development of the infrastructure needed for the growth of the Center.

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