Hospice Partnerships with Academic Entities: Philosophical and Historical Background and Assessment of Future Needs

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Abstract
There is consensus that more research is needed to help improve care at the end of life. Despite the fact that hospices take care of more and more dying persons every year, hospice organizations have not been highly involved in research. The National Hospice Work Group is comprised of hospice organizations that have made promotion of research a high priority. Structured interviews were conducted with members of the National Hospice Work Group to investigate how they think about the role of academic partners in their organizational missions, what their histories of involvement with academic partners are, and what they see as their most important academic needs for continuing to advance the research agenda. Members of the National Hospice Work Group see strategic partnerships with academic entities as essential to the goal of advancing research in end-of-life care.

Introduction
The National Hospice and Palliative Care Organization, the American Academy of Hospice and Palliative Medicine, and the National Institutes of Health have each affirmed the need for more robust research agendas aimed at improving care for patients who are dying.1–3 Persistent deficiencies in aspects of care, such as pain and symptom management at the end of life, reveal a need for more research in end-of-life care. Furthermore, the growth of the hospice movement in the United States makes hospice settings a potentially important and underused setting for end-of-life care research.4

The need for research is clear.5–8 Equally clear, unfortunately, are some obstacles to research. Casarett et al. found that only 19% of hospices surveyed were participating in research.9 These hospices tended to be in urban settings and affiliated with an academic institution. Among the hospices that had participated in research, patient surveys of pain and family satisfaction surveys were the most
common research methodologies used. A very small number of hospices also had taken part in randomized clinical trials.

To explain their lack of participation in research, hospice staff and administrators identified a number of barriers to conducting research in hospice care settings. First of all, some hospice professionals reported that they did not think patients and families were interested in participating in research. These hospice staff members expressed concern that involving hospice patients and families in research would increase vulnerability and compound suffering for patients and families. Other barriers to research in hospice settings have also been identified. These include 1) difficulty obtaining informed consent with frail and often cognitively impaired patients, 2) ethical concerns about subjecting dying persons to the rigors and uncertainties of randomized clinical trials, 3) shortages of staff who can devote time during the workday to research responsibilities, 4) shortages of staff with expertise in data collection and analysis, and 5) lack of access to institutional review boards (IRBs).10–14

In addition, lack of participation in research can also be attributed to philosophical differences between hospice care and mainstream medicine. Hospice care originated as a movement to promote more compassionate care for the dying—care that was not being given by traditional medical practitioners.15 Some think that “burdens” of research may impinge on this compassionate care.

The National Hospice Work Group (NHWG) (see Appendix 1 for NHWG members) consists of organizations for which relationships with academic institutions and promotion of research are high priorities in order to improve clinical care for individuals and recommend health policies that are relevant at the population level. We conducted a series of structured interviews with 17 leaders and education or research directors from member institutions of the NHWG. Interviews focused upon 1) understanding of the role of research and academic partnerships in hospice palliative care, 2) experience with academic partnerships, and 3) particular needs with respect to continuing advancement of the research agenda in hospice palliative care.

In this report, we explore the results of these interviews. Our purpose was to canvas the philosophies and experiences of a number of hospices working with academic institutions, especially in terms of research, and also identify key areas of need among these organizations that might be met by further collaboration with academic entities.

Methods

All members of the NHWG were contacted to participate in a structured phone interview to discuss partnerships between their organizations and academic entities. By academic entity, we mean an institution of higher learning (e.g., college, university, or academic medical center) that has faculty with specific research expertise and an infrastructure to support scholarly work (at minimum, a library and other sources of electronic retrieval, biostatistical consulting services, IRBs, and ethics committees). By academic partnership, we mean a formal relationship, usually including 1) sharing credit for intellectual work, and 2) sharing financial responsibilities for conducting the work.

Members of the NHWG were first contacted by e-mail with a description of the interview project, in addition to the interview questions, and were asked if they would like to schedule a time to participate in the interview. The researcher followed up with all NHWG members who expressed interest in participation and conducted structured interviews.

The interviews (Appendix 2) contained questions focused around four main areas. First, participants were asked to describe their organization in terms of average daily patient census, services provided, and demographic information. Second, participants were asked whether or not their organization had (or has) partnerships with academic entities. If participant organizations had (or have) academic partnerships, they were asked to describe the history of their organization’s involvement with their academic partners.

Third, participants were asked to discuss their philosophical understanding of the role of academic institutions in terms of their organizational mission and their organization’s particular research priorities. Finally, participants were asked what needs (if any) they had that could be met by an academic partner.
Results

Twenty-four individuals were contacted to participate in our structured interviews. Seventeen individuals, or their delegates, participated (70.1% response rate). Three of these 17 individuals manage organizations involved in research oversight and consultation within the hospice industry (excluded from Results section). The remaining 14 individuals work within major hospice care organizations that serve nearly 9,800 patients per day (average daily census = 702 patients/day).

Importance of Academic Partnerships and Research Priorities

We asked each participant to explain why academic partnerships are (or are not) important to their organizational vision. Every participant expressed a commitment to research in hospice care as a motivator for academic partnerships. Even organizations that either have no academic affiliation, or have not been significantly involved in research, expressed enthusiasm for improving hospice care through research; the organizations that have had less involvement in research cite resource and/or geographic limitations (e.g., no research university nearby) as the main reasons for less research involvement. Some participants also expressed areas of concern with respect to partnerships with academic entities, such as fear of bureaucratic issues. Representative quotations that reflect both positive and negative attitudes about academic partnerships are provided in Table 1.

We also asked participants to identify specific organizational research priorities. Some common research priorities include improving the evidence base for why hospices offer a wide array of services that are usually not offered in other medical contexts (e.g., massage therapy, pet therapy, music therapy, and spiritual care), benchmarking best practices, improving pharmacological interventions for pain and symptom management, improving communication between professional caregivers and patients/families by testing different communication strategies and/or styles, and improving end-of-life care with underserved populations. It is worth noting that clinical and community education is also an important reason to form academic partnerships for some hospices. However, the main focus here is the importance of academic partnerships for research promotion.

Finally, we asked participants how they think about the issue of harm in conducting research. Representative quotations that reflect both positive and negative attitudes about academic partnerships are provided in Table 1.

Table 1
Positive and Negative Attitudes About Partnerships between Academic Entities and Hospices

<table>
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<th>Positive quotations</th>
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<tr>
<td>“We need [academic leaders] to help us develop quality products and education to benefit not just our staff and community but the field.”</td>
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<td>“Community hospices have not typically been seen as places for research. Hospices have been seen primarily as service organizations, but I think there can be a nice blending of cultures [in terms of service and research]. We can blend the hospice service [ethic] and the academic priorities of how do you raise important questions [and study them].”</td>
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<td>“Traditionally, hospice has told a lot of anecdotal stories about how wonderful we are, we have a wealth of that kind of information. But we often don’t have statistical data about these stories we tell. If we don’t have this data, then we really shouldn’t be telling the stories. In order for us to be a recognized and valued part of the health care continuum, we have to be able to support what we do statistically.”</td>
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<td>“We think that the real long-term and in-depth knowledge [needs to be better substantiated by research]. We think this is needed to put end-of-life care where it needs to be in this country. And we don’t believe that our organization [or other organizations like ours] has the capacity to make that happen on our own; we think it’s the role of academia to do that; we want to assert ourselves as a partner to advance that purpose.”</td>
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<td>“We believe a strong academic relationship is essential to the goal of leading [the hospice field] forward...The way to make progress is to maximize the resources that we have [in our care organizations] and in the academic institutions [surrounding us].”</td>
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<table>
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<th>Negative quotations</th>
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<td>“The bureaucracy involved in work with major research universities is frustrating — it can greatly impede significant work.”</td>
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<td>“The major issue with [academic entities] is that [partnerships are] often one sided financially. This organization devotes a sizeable resource to our collaborations and to training students, but...universities are very poor at thinking about ways to help [outside] organizations in any kind of systematic way or even in acknowledging the contributions of others. I often think of children when I think of how the university expresses gratitude...As we involve more of our highly compensated staff (mostly MDs) in the teaching effort, the effect on the bottom line is more noticeable.”</td>
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research with hospice patients. Generally, participants did not see hospice patients or families as significantly more vulnerable than other vulnerable groups. Participants also explained that many hospice patients welcome the opportunity to participate in research because it allows them the possibility of giving something meaningful to others (e.g., knowledge that can lead to improvements in end-of-life care). Representative quotations that reflect participants’ attitudes about the issue of harm in research are provided in Table 2.

**Past Participation with Academic Partners**

Eleven of the 13 (84.6%) hospice organizations interviewed have at least one academic partnership. These same 11 have major educational programs for medical, nursing, social work, ministerial, and other professional students. Two of the 13 organizations interviewed sponsor full-time physician fellows in palliative care. All 13 organizations have active community outreach/education programs focused on educating community members on the wide-array of resources available to them in the form of hospice care. For smaller hospice organizations (in terms of average daily census), academic partnerships were described mainly in terms of educational relationships; smaller hospices, even if they have academic partners, are less involved in research, especially research requiring data collection, data management, and statistical expertise such as randomized clinical trials.

Thirteen of 14 (92.9%), including one organization with no academic affiliation, have participated in some form of research. The types of research represented are qualitative research (12 of 14), which includes case study analysis and ethnographic research; descriptive research (11 of 14), which includes survey research; and experimental research, which includes randomized clinical trials (10 of 14) and therapeutic interventions research (non-drug trials) (4 of 14). Only two of 14 hospices we spoke with have their own IRB; most hospices rely on IRBs from academic partners.

**Examples of Research.** A number of the organizations with which we spoke have been or are involved with the Population-Based Palliative Care Research Network (PoPCRN), which initiates, manages, and coordinates studies aimed at improving palliative care in end-of-life settings. Dr. Jean Kutner, co-director of PoPCRN, is a member of the NHWG. PoPCRN studies include the Reducing End-of-Life Symptoms with Touch study, which is measuring the effectiveness of two different forms of touch for patients at the end of life, the Fatigue study, which is examining potential sources of fatigue in patients receiving hospice care, and numerous others. Furthermore, numerous organizations work with pharmaceutical companies and/or sponsoring research institutions to recruit and enroll patients in drug trials. For example, one hospice is involved in a study that is measuring the effectiveness of methadone versus traditional opioid medications on opioid-naïve patients. Other clinical trials have measured the effectiveness of new medications for pain and/or symptom management for persons suffering from neuropathic pain.

Other studies have included measuring changes in patient and/or family satisfaction in response to alternative therapeutic modalities or particular care interventions and comparing hospice care to standard care for minority group patients (African American patients and Hispanic patients in particular).

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<td><strong>Attitudes About Harm in Research with Hospice Patients/Families</strong></td>
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“If we don’t research these patients, we’ll never have the opportunity to help them...we have to encourage [research] and be a part of it. There is always the potential for harm. These are vulnerable patients and families, and you always have to be very careful in thinking through what you are trying to do. But...people understand that [research is] important, and they want to participate. Patients and families are [often] eager for an opportunity to give back.”

“I don’t think you can make one comment that covers all situations...If you are talking about interventional research where studies are monitored by an IRB, and the patient population is given the opportunity to participate, many patients look at an opportunity to participate as an opportunity to leave a living legacy.”

“I think it just depends on what kind of research you are doing. A randomized clinical trial for pain meds is [difficult] because of the population. But I think it’s the same thing that anyone has to deal with in research. [However], if dying people can continue to help others by participating in research, they would often like to do so because they can give back.”
Needs for Advancing Research in Hospice Care

Our participants identified a number of organizational needs that could be met by academic partnerships. Some frequent needs that were mentioned are as follows: research design and implementation, recruitment of subjects for participation in research, data analysis, IRB support, and development and support of a consortium of hospices engaged in research (supported by one or more academic entities) to facilitate multisite research and interinstitutional communication of findings, and enhancement of organizational profiles for donors and grantors.

In summary, NHWG participants think that high quality research is important for improving care at the end of life. Research priorities range from learning better symptom management to building an evidence base for the impact of volunteers on outcomes for patients. Participants acknowledge the fact that hospice patients and their families are vulnerable. However, participants do not see hospice patients and families as especially vulnerable. Nearly all of the hospice organizations with whom we spoke have at least one academic partner and have been involved in some form of research. Qualitative research and survey research are the most common types of research in which participant organizations have been engaged, but drug trials are also common among these organizations. Very few hospices have their own IRB. These national leaders see academic partnerships as essential for continued improvements in hospice care, because academic partnerships can help hospices meet research goals.

Discussion

As the hospice industry continues to grow and more patients receive hospice care, the need for research will also grow. Research in hospices should also be a high priority because 1) it can lead to new therapies that can improve current hospice patients’ quality of life, 2) it can provide patients the opportunity to contribute to the future care of others, 3) it can promote generalizability for end-of-life care research for hospice patients, and 4) it can give patients “collateral benefits” like increased time and attention from professional caregivers. Finally, if research documents better outcomes for hospice versus nonhospice care, this research will provide a basis for continuing public entitlements to pay for hospice care.

Several studies have highlighted the difficulties of conducting research in hospices. First, there are structural difficulties. Most hospice staff members are not trained in data collection, statistical analysis methods, or research ethics. Consequently, most hospices do not have IRBs or resources to support IRBs. Further, hospice staff members express concern that research procedures would require more time than they can afford to dedicate to non-caregiving activities. Research efforts are also complicated by the fact that most hospice patients have average lengths of stay less than three weeks, and 10% of hospice patients elect hospice care on the last day of life.

There are also ethical difficulties with conducting research in hospices. Some worry that dying persons are too vulnerable to participate in research. For example, rates of cognitive impairment are high for terminally ill patients. Not only does this reduce the potentially eligible pool of patients for research, but hospice staff members are also generally not equipped to determine competency. This makes informed consent particularly difficult to obtain. Another reason to worry is that dying patients who may suffer from severe pain may be more prone to the “therapeutic misconception” when asked to participate in research. Others express concern that study design issues, such as exposing dying patients to placebos, makes research with dying patients inappropriate.

The practical and ethical difficulties of conducting research in hospices have led to numerous challenges for researchers to overcome in the hospice setting. These challenges include an enduring inability to recruit patients, even after extensive recruitment efforts and administrative problems with IRBs inexperienced in the area of palliative care research. Nonetheless, experts agree that though researchers ought to use great caution and care when recruiting dying patients for participation in research, dying patients do not represent an especially vulnerable group. Some argue that researchers are morally obliged to
conduct research with dying patients, because it is the best way to work toward improvement of care at the end of life. Therefore, dying patients should be allowed to participate in research like other patient groups.

Despite difficulties, high quality research can take place in the hospice setting. This study highlights the importance of formal partnerships between hospices and academic entities for advancing research. These partnerships can ameliorate many of the difficulties posed by research in hospice settings.

This study recommends that academic entities be prepared to fulfill a number of key roles for hospices that want to engage in research. Academic entities should be prepared to share IRBs with community hospices. They should be willing to train hospice staff in research ethics and basic data collection methods. Academic entities should also be prepared to offer biostatistical consulting services in order to help hospices interpret data. Finally, academic entities should help hospices secure grant monies by partnering with hospices in research design and sharing professional resources with hospices. However, more applied research on how academic entities can better serve hospices in their research efforts is needed.

There are potential barriers that academic entities have to navigate in order to promote research. Most institutions with IRBs are hesitant to support research involving researchers who are not directly employed by the institution (e.g., professional staff in community hospices). Sharing IRBs with community hospices may pose challenges for academic centers to assure appropriate training in clinical investigation for hospice staff and documentation of that training. Academic centers may also have difficulty assuring that there is a common standard of quality in data collection across sites. Systemic and bureaucratic issues may loom large, but it is important for the research community to negotiate institutional processes so that high quality research can be supported in the hospice setting.

Many community hospices may not be able to compensate academic entities appropriately for their consultative work or provide the appropriate “in kind” resources to support research that is not directly funded by grants. Creative ways of ensuring that financial responsibilities are shared appropriately is crucial for productive partnerships. Though beyond the scope of this project, hospices also have much to offer academic entities. Hospices can advise researchers about the most pressing research needs in hospice settings. Hospices can help academic entities incorporate systems for measuring quality of dying in their medical centers. As academic entities offer a range of services to hospices, hospices also have a range of experience and expertise to offer to academic entities.

A number of hospice leaders expressed hope for forming a consortium of community hospices engaged in research that can be coordinated and overseen by capable academic entities. This might offer a way to overcome barriers on both sides. First, the consortium would require a strong financial base to support all involved parties. Second, the consortium would allow for standardization of support needs and procedures for building research infrastructure between hospices and academic entities so that quality research can be conducted more easily and efficiently in the hospice setting. Standardization along these lines could be communicated widely and replicated elsewhere. Third, a consortium might allow smaller community hospices with fewer patients and less resources to take part in research by drawing upon resources within the consortium. Fourth, a consortium would allow for large-scale, multisite research that could transcend the limitations of studies taking place among homogeneous patient populations or professional cultures. Finally, formation of a consortium would allow for a broad sharing of expertise across organizations and institutions.

This study has some limitations. Those contacted in the NHWG who did not respond to the initial request for an interview may represent a cohort of NHWG members less interested in academic partnerships and research. Second, the NHWG is not representative of the typical small community-based hospice in the United States. The NHWG is comprised of industry leaders that are also some of the largest hospice care organizations in the country. In addition, there are many hospices outside of the NHWG who have substantial research infrastructures. It is worth noting, however, that because of their size and
resources, hospices like those in the NHWG are more likely (and more equipped) to be involved in research, and they are also appropriate leaders for research efforts.

Despite its limitations, this study holds important findings about why academic partnerships are important and what the most pressing academic needs are for hospices interested in promoting research. Academic entities need to think strategically about how to best serve the hospice community in its efforts to improve end-of-life care through high quality research. This includes how to put institutional procedures in place to facilitate partnerships with hospices. Hospices not engaged in research might also be encouraged to participate in research by understanding why some industry partners see research as important.

There is consensus that more research is needed in end-of-life care in hospice settings. There are significant barriers to this research. This study notes the importance of partnerships between hospices and academic entities for navigating barriers and supporting research efforts for improving end-of-life care.

References


Appendix 1

National Hospice Work Group Members

True Ryndes, ANP, MPH, President and CEO, National Hospice Work Group
Gretchen Brown, MSW, President and CEO, Hospice of the Bluegrass
Samira K. Beckwith, CHE, ACSW, President and CEO, Hope Hospice and Palliative Care
Carolyn Cassin, MPA, CEO, Jacob Perlow Hospice, Beth Israel Medical Center
Jan Cetti, BSN, MS, President and CEO, San Diego Hospice
Deborah S. Dailey, MBA, President and CEO, Hospice of Dayton
Malene Davis, RN, CHPN, MBA, President and CEO, Hospice Care Corporation
Dottie Deremo, MSN MHSA, RN, CNAA, CHE, President and CEO, Hospice of Michigan
Susan Drongowski, RN, MA, President and CEO, Nathan Adelson Hospice
David English, DBA, President and CEO, Capital Hospice
David Fielding, BA, MS, President and CEO, Hospice of Palm Beach County
William E. Finn, MBA, President and CEO, Center for Hospice & Palliative Care
Amber Jones, MEd, BA
Jan Jones, RN, BSN, FAAMA, President and CEO, Alive Hospice, Inc.
Jean Kutner, MD, MSPH, Director, PoPCRN, University of Colorado Health Sciences Center
Mary Labyak, MSW, President and CEO, Hospice of the Florida Suncoast
Jeannee Parker Martin, President, The Corridor Group
Karen Nichols, BSN, President, Valley Hospice, Inc.
Dottie Pitner, RN, BSN, MM, President and CEO, Palliative CareCenter and Hospice of the North Shore
David Rehm, MSW, Regional Vice President, VistaCare
Don Schumacher, PsyD, President and CEO, National Hospice and Palliative Care Organization
David Simpson, Executive Director, Hospice of the Western Reserve
Beverly K. Sloan, BS, MPH, President and CEO, Hospice of Metro Denver
Christy Whitney, RN, MS, President and CEO, Hospice and Palliative Care of Western Colorado

Appendix 2

An Investigation of the Needs of a Select Group of Hospice (and Palliative Care) Organizations and the Possibility of Academic Collaboration

Name of Participant(s):
Name of Organization:
Occupational Title:
Date of Conversation:
Questioning Route:

Opening Questions

a) Approximately how large is your organization in terms of patient population?
b) What kinds of services do you provide?
c) What are the demographics of your patient population?

d) Have you partnered with academic institutions in the past? (If the answer is “no,” I will move to transition questions)
e) What have these partnerships consisted in?
f) What were the goals of these partnerships?
g) How have these partnerships been successful?
h) How have these partnerships been unsuccessful?
i) Who provided the IRB for research—your organization or the academic partner? (Do you have an in-house IRB you prefer to use, or no?)

j) What is your perspective generally speaking about the ethics of research in hospice palliative care? Do you see more potential for harm in this kind of research than other kinds of research?

k) How have research relationships you have had in the past been structured financially?

Transition Questions

l) Given your experience and your hopes for the future of your organization, how do you think about the role of an academic institution in your organization’s mission?

m) What are the particular research priorities and goals of your organization?

n) How would you describe the research culture in your organization? How do you think a project such as a randomized clinical trial for a pain medication would be received by your professional staff?

Key Questions

o) How do you think a partnership with the Institute on Care at the End of Life can help your organization?

p) What needs does your organization have that you think a partnership with the Institute on Care at the End of Life can meet?

Ending Questions

q) Of all the needs we discussed, which do you think is most important in terms of a potential partnership with the Institute on Care at the End of Life?

r) Is there anything we have missed that you would like to discuss?