“How can clinicians with diverse backgrounds and training collaborate with one another to care for patients at the end of life?”

NURSING HOME / HOSPICE PARTNERSHIPS

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INTRODUCTION

All people deserve the best possible palliative care available, regardless of where they reside. For many years hospice care programs have been working in close collaboration with nursing homes (NHs) to offer holistic, interdisciplinary end-of-life care to NH residents and their families. As more and more Americans grow older, live longer, and require 24 hour skilled nursing care, the continuation of NH/hospice partnerships can help to ensure that NH residents in their final years and months of life, and their families, receive high-quality end-of-life care that honors their wishes (Hirschman et al., 2005). However, the road to successful NH/hospice partnering is not always smooth (Hirschman et al., 2005; Parker-Oliver & Bickel, 2002; Wetle et al., 2004). The establishment of interprofessional and interorganizational collaborations is challenging in itself, but NHs and hospices in addition must often navigate (at least perceived) conflicting regulatory requirements. Even so, it appears attempts at achieving success in this partnership are beneficial (Baer & Hanson, 2000; Hirschman et al., 2005; Parker-Oliver & Bickel, 2002; Wetle et al., 2004).

This monograph profiles the NH/hospice partnership using interview information from collaborating administrators and staff. It provides a framework for this information by first discussing end-of-life and hospice care in NHs and the challenges of interprofessional and interorganizational collaboration, both in general and specifically for collaborating NHs and hospices. We conclude this monograph by discussing our views and those of others’ on factors leading to successful collaborations and high-quality end-of-life care in NHs.
The Aging U.S. Population and End of Life Care in Nursing Homes

With the growth in the aging population in the United States, the NH has become a common site of death. In 1989, 19% of Americans died in a NH. A short eight years later, one in four Americans died in a NH (http://www.chcr.brown.edu/dying/factsondying.htm). This rate varies across the United States, with some states having more than one in three persons die in a NH. This striking change in demography requires rethinking on how we provide NH services for dying persons and their families. This rethinking is especially needed since research supports the notion that pain and symptom management in NHs is less than optimal (Bernabei et al., 1998; Ferrell, 1995; Teno, Weitzen, Wetle, & Mor, 2001; Wagner et al., 1997), and thus, raises a concern that the quality of care at the end-of-life in NHs may need improvement.

Nursing home residents in the final phase of their lives have more intense and different physical, psychosocial and spiritual needs than do other NH residents. Rather than a focus on restoration or on prevention of decline, care of NH residents requires a focus on palliation--on the management of the symptoms accompanying terminal decline such as pain and dyspnea and on supporting the resident and family towards a meaningful life closure. However, the disturbingly high prevalence of unrelieved pain in NHs (Bernabei et al., 1998; Ferrell, 1995; Teno, Weitzen, Wetle, & Mor, 2001; Wagner et al., 1997; Won et al., 1999) raises concerns about the quality of care for NH residents. Considering that pain intensity increases as death nears (Morris, Suissa, Sherwood, Wright, & Greer, 1986) and that one in four older adults in the United States die in NHs, (http://www.chcr.brown.edu/dying/factsondying.htm) adequate pain management for dying NH residents is critical to achieving high-quality end-of-life care in the United States. In addition to concerns about pain management, high and variable rates of hospitalization in the last 30 days of life in the NH (Miller, Gozalo, & Mor, 2001) suggest care for NH residents at the end of life is fragmented and that dying residents may be exposed to iatrogenic disease and delirium that can decrease the quality of life (Creditor, 1993). Still, many NHs provide compassionate, competent, and coordinated care; however, NHs are beleaguered by chronic staff shortages, high staff turnover and with inadequate reimbursement which can adversely affect the quality of care.

Hospice Care in Nursing Homes

In these challenging times, hospice represents a means by which to bring existing resources and expertise into NHs. Nursing home staff and attending physicians possess varying knowledge
regarding palliative care and end-of-life symptom management. Education is one means to remedy this uneven expertise, but such education in NHs must be continuous so to accommodate the large turnover of aides and nurses at many NHs, and is hindered by staff shortages. In fact, research studies have supported the notion that staff education alone does not result in improved quality of end-of-life care (Ersek & Wilson, 2003). The NH/hospice collaboration as a means to improving end-of-life care in NHs acknowledges the limitations of such improvement using the resources of NHs alone.

Hospice care provision in the United States (U.S.) began in the early 1970’s in response to the need to ameliorate the unremitting physical and psychological pain and suffering which may occur in the process of dying. In 1982 the U.S. Congress passed legislation allowing payment for hospice care provided to terminally persons [i.e., those with certified prognoses of 6 months or less to live (if the disease runs its normal course)] who are qualified to receive government Medicare health care benefits (generally, persons 65 years of age and older or younger persons with permanent disability) (Tax Equity and Fiscal Responsibility Act of 1992 (TEFRA-82), (P.L. 97-248). Although the hospice benefit allowed for payment of inpatient hospice care, the intent of the Medicare hospice benefit was for care to be provided primarily in a person’s home and, for the most part, Americans residing in NHs did not have access to the hospice benefit. This changed when, in 1985, the US Congress passed legislation to extend the Medicare benefit to persons living in NHs (Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA-85), (P.L. 99-272). The Omnibus Budget Reconciliation Act (OBRA) of 1989 resulted in greater availability of the hospice benefit in NHs since it clarified payment mechanisms for dually eligible (i.e., Medicare and Medicaid eligible) residents who receive hospice care (Miller, Mor, & Coppola et al., 1998). It is estimated that approximately 24% of Medicare hospice care is provided in NHs (Miller & Mor, 2001).

Nursing homes can offer hospice care to dying residents by developing working relationships (including formal contracts) with Medicare approved hospice providers (Gage et al., 2000). Like all hospice beneficiaries, by electing the Medicare hospice benefit, NH residents agree that the hospice has full responsibility for managing their plan of care. By enrolling in the Medicare hospice program residents also waive their right to receive standard Medicare benefits related to their terminal illness, including all curative treatment, unless they chose to “disenroll” from hospice, something that can be done without jeopardizing reenrollment. With hospice enrollment, NH residents and their families receive physical, psychosocial and spiritual support and care from a hospice interdisciplinary team as well as drug coverage for medications related to their terminal
illness; the NH continues to provide the care covered through Medicaid or private pay “room and board.” Residents who receive Medicare Part-A skilled nursing facility (SNF) care at present cannot simultaneously access Medicare hospice; thus, this group representing approximately 34 percent of NH decedents (Rhoades & Sumner, 2000) cannot access Medicare hospice without disenrolling from the Medicare SNF benefit.

Benefits of Hospice/Nursing Home Partnerships

There are many potential benefits to a joint approach and partnership between hospices and NHs but key is the experience of the resident and family as a result of coordinated resources and efforts. The potential benefits of partnership to residents and their families / significant others include:

- Access to care expertise in both long-term care and hospice care;
- Additional attention from increased number of people involved in care;
- Access to counseling and spiritual care disciplines to meet the intense and varied needs that surround the end-of-life experience;
- Access to hospice volunteers who spend time with residents and provide diversional and quality of life activities that NH staff do not have time to provide;
- Access to hospice volunteers who assist and support families / significant others so they can spend more quality time with residents;
- A continuity of care team providers;
- Coverage of medications, medical supplies and equipment related to terminal illness;
- Access to professionals that specialize in supporting residents and families to a more meaningful life closure;
- Additional support for family members providing care, and anticipating life without their loved one; and
- Bereavement support for family for up to 12 months after the resident has died

Potential benefits of partnership to NHs include access to / assistance with:

- Additional professionals to help with care planning and provision;
- Interdisciplinary team expertise in the specialty of palliative care;
- Shared expertise in pain and symptom management;
- Ethical decision making consult service;
- Family decision making counseling;
• Hospice nursing assistant visits to supplement the increasing intensity of hands on care;
• Validation of residents’ palliative care (and care outcomes) needs to an outside reviewer (such as in conjunction with federal government quality indicator outcomes that if observed on non-palliative care patients would be considered negative outcomes);
• Expertise in documenting palliative care assessment, interventions and expected outcomes that differ from restorative/rehabilitative outcomes;
• Volunteers to sit with resident so they are not alone;
• Grief support for other residents;
• Grief support for NH staff who experience cumulative loss with the death of many residents; and
• Education for staff on palliative care.

For hospices, the potential benefits of partnership include access to:
• Professionals expert in chronic residential care;
• Nursing home staff who know and support the resident as their extended family;
• Extended team to help in care of resident 24 hours a day, seven days a week;
• Clinical expertise in chronic care; and
• More people to serve near life’s end.

Research on the benefits of hospice care in NHs has focused on medical dimensions of support. This research has shown hospice residents, compared to nonhospice residents, to experience fewer hospitalizations near the end-of-life, have fewer invasive treatments (i.e., enteral tubes, intravenous fluids, and intramuscular medications), and receive analgesic management for daily pain that is more in agreement with guidelines for management of chronic pain in long-term care settings (Miller, Gozalo, & Mor, 2001; Miller, Gozalo, & Mor, 2001; Miller, Mor, & Teno, 2003; Miller, Mor, Wu, Gozalo, & Lapane, 2002). Family members of persons who died in NHs perceived improvements in care after hospice admission; they cited fewer hospitalizations and lower levels of pain and other symptoms after hospice admission (Baer & Hanson, 2000). Nonhospice residents in NHs also appear to benefit from hospice presence in the NH. Research has found nonhospice residents residing in NHs with a greater hospice presence (i.e., a greater proportion of residents enrolled in hospice), versus in homes with no or a limited hospice presence, to be less frequently hospitalized at the end-of-life and to more frequently have a pain assessment performed (Miller, Gozalo, & Mor, 2001; Wu, Miller, Lapane, & Gozalo, in press). Considering the cited
potential and actual benefits, collaboration seems to be a care alternative worthy of pursuit. But, what are the challenges?

The Nursing Home / Hospice Partnership and the Challenges of Interorganizational and Interprofessional Collaborations

The coordinated provision of hospice care in NHs is challenging; the barriers integral to interprofessional and interorganizational collaboration discourage some providers from engaging in such partnerships and others from benefiting fully from the potential synergy these they can afford. The nurses, aides, social workers, clergy and physicians employed by hospices and NHs receive training and experience in distinct specialty areas and in environments having different care philosophies, approaches and goals of care.

Barriers that are attributed to interprofessional collaboration include 1) ascribed and perceived occupational status; 2) perceived importance of occupational knowledge; and 3) distrust of perspectives of other occupational groups (Mackay, Soothill, & Webb, 1995). Distrust, in particular, is evident by the suspiciousness that NH and hospice staff have for each others approaches to care; for example, hospice philosophy supports the rights of dying NH residents to refuse to eat, but NH staff often actively intervene when dying residents refuse to eat, in part because of fear of surveyor citation for substandard care if a resident is malnourished or dehydrated (Gage et al., 2000). Knowledge differences stem from the fact that palliative care has not been included in core training for nurses, nursing assistants or other disciplines outside of hospice. Hospice staff has received additional training to develop the competencies to deliver the specialty of palliative care; they are experts in end-of-life care, and NH staff are experts in long-term care.

Barriers ascribed to interdisciplinary collaborations overlap somewhat with the summarized interprofessional collaboration barriers, but also appear to add to our understanding of the challenges associated with the collaboration of NH and hospice staff; these barriers are 1) varying professional or personal perspectives; 2) role competition; 3) role confusion; and 4) turf issues (Abramson & Mizrahi, 1996). Role competition and turf issues may be particularly relevant when considering the NH/hospice collaboration; this stems in part from the perception by some that hospice staff are the “experts” brought in to rescue residents from the incompetent NH staff. Medicare regulations that give hospice full responsibility for managing a NH resident’s plan of care once hospice care is elected may add “fuel to the fire” as NH staff may feel they’re abandoning their residents to hospice—residents they may have cared for several years. Additionally, NHs do not feel these regulations relieve them of responsibility if problems arise (Gage et al., 2000). Leipzig and
colleagues (2002) refer to this dilemma—of ultimate responsibility versus shared decision making—as the “Achilles heel” in interdisciplinary relationships. The fact that one profession is considered to be ultimately responsible can serve to undermine a relationship of collaborative care planning and provision. The question of who is in charge is often complex, with legal, ethical and professional ramifications.

Hospices and NHs often perceive regulations and its oversight as a barrier to collaboration. Reports from hospice and NH representatives, and from state surveyors, highlight the divergent goals and orientation of these professionals. Nursing home staff and their surveyors view the NH’s role as restoring health or providing rehabilitative services while hospice staff view their role as providing palliative care (Gage et al., 2000). So, some NH administrators may be hesitant to collaborate with hospices because they fear surveyor citation when care approaches are different than what regulations encourage (such as the honoring a dying resident’s wish not to eat or drink when regulations encourage sustenance, which may translate into the provision of IV fluids or the insertion of a feeding tube). Additionally, the Office of Inspector General (OIG) has previously targeted the NH/hospice collaboration for scrutiny. An OIG investigation led to questions regarding the integrity of some NH/hospice contractual relationships as well as to questions regarding some residents’ hospice lengths of stay (US DHHS, 1997). While for the most part contract language / contractual practice concerns have been addressed by providers, the fear of continued scrutiny may for some providers result in a hesitancy to collaborate. Another barrier concerns Medicare reimbursement policy. As discussed earlier, residents receiving Medicare Part-A SNF care (related to their terminal illness) cannot access Medicare hospice without forfeiting Medicare SNF coverage. For a Medicare SNF resident who is Medicaid eligible, receipt of Medicare reimbursed hospice care means the NH must relinquish the resident’s Medicare SNF payment and instead receive the lower Medicaid per diem rate. This policy may be a powerful incentive for some NHs not to collaborate with hospices, or for those collaborating, not to refer Medicare SNF residents to hospice.

Even in the face of the above challenges, NHs and hospices successfully partner to provide high-quality end-of-life care in NHs. The next section characterizes these partnerships.
Overview and Methodology

In conjunction with a Retirement Research Foundation (RRF) funded study, an effort began to better understand the provision of hospice care in NHs (Miller, Mor, Teno, 2000). A major aim of this study was to examine interorganizational practices between collaborating NHs and hospices. Dr. Miller and research staff performed site visits and interviews to gain knowledge of collaborating practices, and to identify problematic aspects of the relationship; information from these interviews are shared here. In this same RRF study, interviews were conducted of family members of residents who had been cared for by hospice. While family interviews did not inquire specifically about the NH/hospice collaboration, numerous comments reflected on the success and/or problems with this collaboration; some of these comments are also shared here.

Geographic sites for this study were chosen based on the amount of hospice care in NHs provided in counties within states; because large sample numbers were needed to accomplish some study goals, we targeted hospices providing much hospice care in NHs. Using data from the Center from Medicare and Medicaid Services (CMS) OSCAR NH survey data, state maps for states with high hospice concentration were created. Using these maps counties within these states with the highest concentration of hospice recipients in NHs; large hospice providers within these counties were contacted to request their study participation. Six geographic sites were chosen: San Diego, CA; Tampa/St. Petersburg, FL; Chicago, IL; Lexington, KY; Buffalo, NY; and Fort Worth, TX. Two hospice providers participated at each site, except for in Buffalo where one hospice participated. Five of the 11 participating hospices were members of the National Hospice Work Group, Inc., a consortium of the nation’s largest non-profit hospice providers. An attempt was made to interview administrators and staff in two NHs that contracted with each participating hospice—one NH with a greater number of hospice referrals and one with a lower number of hospice referrals. A total of 19 NHs agreed to participate in the interviews; for three hospices we interviewed staff at only one NH.

After field testing and revising the interview instrument, sites visits were made and group interviews were conducted by the same interviewer at all sites. Groups most frequently included the administrator / chief executive officer, the director of nursing and/or a nurse supervisor, a social worker, and the chief financial officer. The interview was primarily quantitative with open ended responses; it gathered information on coordination of administrative and clinical aspects of care as
well as on staffs’ perceptions regarding the influence of hospice care on quality, both for hospice and non-hospice dying residents and their families / significant others. During the site visits, data were obtained on the average number of residents receiving hospice on any given day and on a NH’s average number of total residents on any given day (from 8/1/97 through 7/31/98). From these data we determined the proportion of NH residents enrolled on hospice on any given day—the NH’s hospice concentration.

**Characteristics of Collaborators / Collaborations**

The organizations studied were experienced collaborators; only one provider, a hospice, had less than three years experience in collaborating. On average, hospices had eight years experience collaborating with NHs, while NHs averaged six years. However, the volume of hospice referrals (represented by the hospice concentration variable) was not strongly correlated with the number of years NHs were collaborating with hospices; three NHs with three or more years collaborating experience still had hospice concentrations of less than two percent, while the NH with the highest hospice concentration (of 14%) had collaborated with a hospice for only two years. The average NH hospice concentration was four percent.

Nursing homes partnered with a limited number of hospices, but hospices had contracts with multiple NH providers. Ten of the 11 hospices had over 25 active NH contracts, and five of the 11 programs had over 60 active contracts. Hospices in almost all cases initiated the collaboration and their philosophies for choosing NH collaborators varied. Some hospices felt that their mission required them to offer services in any NH, regardless of the NH’s quality of care reputation; others avoided contracting with NHs having poor quality of care reputations. Generally, especially when beginning to contract with NHs, hospice staff stated that they started small and chose collaborators with similar missions and values—collaborators who shared their vision and with whom it would be “most likely to work”; these are common and important considerations when initiating interorganizational collaborators (Kastan, 2000; Mulroy, 1997). Ten of the 19 NHs had only one or two hospice contracts and only one NH had over six contracts. In some study locations this observed difference was the result of state regulations restricting the number of hospice providers operating in a county or another designated geographic area (i.e., hospice certificate of need legislation). However, interviews with NH staff revealed limiting the number of hospice collaborators was a deliberate choice to limit the amount of diversity with which NH staff had to contend. Even when NHs had contracts with more than one hospice provider, staff indicated strong preferences for one hospice provider over another. Two frequently cited reasons
for a preference included hospice staff stability (i.e., hospice sends the same staff members to the NH) and reliability (i.e., staff visit when they say they are going to visit).

Nursing home chief financial officers indicated few instances of billing disputes between the hospices and NHs, but three of eleven hospice chief financial officers found the shared billing to be problematic. When there were billing disagreements, these appeared to be related to coverage for medications or supplies; however, most hospices had procedures in place to advise the NH of hospice coverage upon a resident’s hospice admission, particularly which medications will be covered under the hospice benefit.

Most NH staff reported receiving hospice training on Medicare hospice admission criteria and/or reported receiving referral guidelines for persons with non-cancer terminal illness. Reasons for referral most frequently cited were the presence of poorly managed pain and family problems in dealing with a resident’s imminent death. Attending physicians were noted to only rarely initiate hospice referral; per interviews, physician involvement appeared to occur most often after hospice had been suggested to residents and their families by NH nurses or social workers. Nursing home nurses and social workers appeared to be the “gate keepers” to hospice. Besides NH staff, families also requested hospice referral; according to interviews, this occurred at times because families observe another dying resident receiving the additional services provided by hospice and they want the same level of care for their loved ones. Staff indicated that only a small proportion of patients are enrolled in hospice upon NH admission. These persons, according to interviewees, can no longer receive hospice in their homes in the community or come from a hospital where a discharge planner identified the need for hospice referral.

Collaborative Tensions and Successes

Based on interviews, the collaborations studied appeared to function well, but this varied and some classic interprofessional and interorganizational problems were present. According to reports, there appeared to be some professional distrust as well as some disagreements regarding care philosophies. Staff portrayed new collaborations, especially, to be fraught with suspiciousness of hospice staff and uneasiness with different care approaches such as the higher dosages of opioids recommended by hospice. It was also clear that many NH staff felt hospice staff did not always fully appreciate their expertise, or the implications of the long-standing relationships they had with their residents.

Even though hospice regulations state hospice assumes responsibility for coordinating care of the NH hospice resident, NH staff stated they had the ultimate responsibility for the resident (and,
legally and ethnically, this responsibility is probably a shared one). In staff interviews, the collaboration was infrequently described as a partnership, but rather it appeared to be viewed more as consulting relationship, with hospice being the experts in palliative care and bereavement support. Some NH staff stated hospice nurses presented as arrogant, but other staff stated hospice nurses made NH nurses feel their role is important. Several administrators and/or nurse supervisors cited the development of friendships between NH and hospice nurses, and between aides. Many NH staff stated hospice staff needed to better understand the NH industry and “what they’re up against.”

**Specific aspects of care coordination**

In accord with Medicare regulations, hospice staff for the most part stated they coordinated the care provided to residents enrolled in hospice. Almost all NH groups interviewed (18 of 19) indicated the care planning process was coordinated with the hospice care providers. However, staffs at five NHs stated hospice staff were often unable to attend NH-based care planning meetings, sometimes because the meeting time or date was moved by the NH to accommodate a schedule change. In no NH did the NH/hospice care plans appear to be totally integrated into one documented care plan, but NH staff stated that they included hospice plans and interventions in plans of care. In most cases, hospice staff said they prepared a separate plan of care. Nursing home staff stated they learned the specifics relating to a hospice visit by reading hospice visit notes, which were included in residents’ records, and often, by conferring verbally with hospice staff after a visit occurred. Most NH and hospice staff stated hospices are notified when hospital admission is being considered; they also said hospices are asked for assistance when physicians are resistant to (hospice) recommended dosages of opioids.

Both NH and hospice staff discussed how professional and philosophical differences regarding approaches to care (e.g., the management of pain, the used of feeding tubes, etc.) diminished the longer a hospice was partnering with a NH. Still, staff from five of the eleven hospices and three of the nineteen NHs said NH staff were not totally receptive to hospice approaches to care; this did not appear to differ by the years of collaborating experience.

According to interviews, for most NH residents who enroll in hospice, their attending physician is the NH medical director rather than a physician in the community. Those interviewed described the hospice medical director’s role as that of a consultant or advisor to the attending physician. Interactions between the attending physician and hospice medical director were said to occur primarily via telephone, and most often to concern pain management issues. Most attending
Physicians were described as receptive to a patient/family’s hospice choice and to recommendations made by hospice medical directors, but some remain resistant. According to staff, physician conflicts relating to differing approaches to care diminished over time; some hospice staff attributed this in part to in-service education provided by hospices to the medical community.

**Perceived Hospice Influence on Quality of Care**

Staff from 18 of the 19 NH interview groups stated hospice care positively influenced the quality of end-of-life care for NH residents who enrolled in hospice, and their families/significant others, as well as nonhospice residents. (The one NH group to not agree with this hospice benefit had been contracting with hospices for seven years, but still made hospice referrals very infrequently.) When NH staff discussed their perceptions of the benefits of hospice enrollment for hospice residents/families, the extra one-on-one care and the psychosocial support to residents and their families/significant others were most frequently cited. Three major themes to emerge from qualitative analysis of the open-ended questions are listed and described below; some frequently heard comments relating to the themes are also listed.

1) *Hospice allows for "one-on-one" care—a little bit extra*

   This theme was commonly discussed by NH staff. Many staff stated that although they worked hard, hospice was able to give their residents support for which NH staff did not have adequate time. Examples of responses for this theme are:
   
   Hospice provides an “extra set of hands / hearts”.
   
   Hospice is “very important for family and resident—lot of extra support and guidance given.”
   
   Hospice gives “extra TLC”.
   
   “Even though nursing facility staff give 110%, the extra help is needed.”

2) *Hospice provides big psychosocial support to residents and families.*

   Staff frequently voiced this sentiment. Nursing home staff were particularly appreciative of the psychosocial support provided to family members; it appeared this additional support was considered very needed. Examples of responses are:
   
   “You know what, that’s a really big one—that they’re there for the family.”
   
   “Patients are more secure, less anxious.”

3) *Hospice influences quality of care, but nursing home provides good care / has good staff.*

   This theme prevailed through many of the NH responses; it appeared important to staff that their knowledge and skills to be recognized, perhaps because hospice presence threatens staff’s
perceived status and importance. Views of hospice benefits were often qualified by a statement regarding the similar knowledge and skills of NH staff. Examples of responses are:

Yes, but “it goes both ways”. We are “already a caring staff.” Hospice “sets another example.” “Hospice benefits from providing care in this nursing facility.”

The “… eyes and ears are here. Nursing facility staff provide a reality check for hospice staff. They know what to expect from other nursing homes” (because they’ve worked in this nursing home).

Sometimes NH staffs’ appraisal of the benefit of (and need for) hospice differed. For example, at one NH, the palliative care skills of the NH nurses was viewed differently by varying levels of management, as reflected in the below quote.

*Nursing Home Administrator:* “Staff really give good care--sometimes skills exceed those of hospice nurses.”
*Nurse Supervisor:* “Influence of hospice depends on patient and on needs. For very needy patients (and especially families) hospice can be a very positive thing. Most nurses at the nursing home are up on pain medication. Extra time spent by hospice with patient/family is helpful.”

*Director of Nursing:* “Three of ten nursing home nurses may have the comparable education as hospice but the others don’t. Hospice is very beneficial.”

Nursing home staff were also asked whether they felt hospice influenced the care of nonhospice NH residents. When considering the nonhospice residents, the most frequently mentioned benefit was hospice’s influence on pain and symptom management. As discussed below, two major themes emerged from qualitative analysis of responses to this question.

1) *Hospice presence influences pain and symptom management*

Frequently those interviewed indicated that, through observing hospice care provision and interacting with hospice staff, NH staff gained palliative care expertise. The following quote is a response reflective of this theme, and is representative of the “spill-over” effect voiced by many interviewees.

*From a nursing home administrator--*

“The nurses being exposed to this, taking care of the hospice patients, sharing things or problems with the hospice people . . . . it does, it does. You can see it the way the nurses handle terminal patients that are not on the hospice program.”
(What’s different?) “What’s different is that they are more focused on comfort measures. They are focused on the pain management, make sure they are comfortable. And, because of the experience in dealing with the doses of those medications they more or less know the appropriate dose that the doctor can order.”

2) Hospice has changed attitudes of nursing home staff

There were numerous comments by administrators and supervisors on how the presence of hospice had changed staff attitudes (and related behaviors) regarding end-of-life care in the NH. Typical quotations illustrating this theme are below.

Nurses “wanted to save the world”. Hospice has changed their views—“seeing patients die in comfort has changed them.”

“Staff now know it is okay to cry.”

“Staff now know it is okay to hold a patient’s hand.”
Management planning and other activities can be instrumental in preventing and reducing conflicts arising from interprofessional barriers and organizational incompatibilities (Gulliver, Pedck, & Towell, 2002; Iles & Auluck, 1990; Kastan, 2000). In the case of the NH/hospice collaboration, needed are policies and procedures relating to the need for coordinated billing, staffing, and other operations; the coordination of care practices across program and staff lines; and the consistent and coherent communication at the administrative, clinical and staff supervisory level. Formulating these policies and procedures and educating staff regarding their roles must be done with a clear understanding of each organization’s internal and external environment; for example, the differing regulations and oversight of hospices and NH must be clearly understood when formulating policy and procedures so they will be congruent with regulatory and legal requirements.

In addressing interprofessional barriers, roles and accountability should be clearly defined; it is desirable to have an ongoing dialogue between professionals in each organization to discuss issues and feelings that arise. However, while role conflicts can be lessened with clearly defined role boundaries and an understanding of these boundaries by collaborating staff, flexibility and the added benefit of the diverse perspectives afforded by collaboration should not be lost by boundaries that are too rigid (Butterill, O’Hanlon, & Book, 1992; Gulliver, Peck, & Towell, 2002).

Mutually respectful relationships are a must. Professional pride and distrust by differing professionals can be approached through education and by face-to-face discussions of roles and responsibilities (Sharples, Gibson, & Galvin, 2002; Gulliver, Peck, & Towell, 2002). To help assure collaborative success, Gulliver and colleagues (2002) feel staff must consider the alliance a partnership and management must have onsite involvement and designate a full-time project director. Kastan (2000) emphasizes the need for “boundary spanners;” these people identify and articulate common ground to “bridge the gap” between organizations and should be identified in each collaborating organization. In relation to common ground, as discussed earlier, a shared mission is considered essential to collaborative success (Mulroy, 1997); the goal of the provision of high-quality palliative care and support to NH residents and their families is such a shared mission. We might ask then: Are NH and hospice goals intrinsically different?
Learning Each Others’ Culture and Systems—Are Goals and Approaches to Care Really Different?

The existence of cultural and system differences as well as similarities between hospices and NH often contribute to challenges in partnership. What drives NH culture and what drives hospice culture sometimes differs. Contributions that may appear disparate are often misunderstandings and/or a come down to a simple lack of knowledge.

Hospice staff bring expertise in palliative care, but may not have an understanding of the nursing facility environment or regulations. Likewise NH staff contribute expertise in long-term care, but may not have an understanding of the specialty of palliative care or hospice systems and regulations. The most successful partnerships recognize these differences and assure that staff from each setting develop basic knowledge and expertise in each other’s specialty. Successful collaborations happen when hospice staff posses a working knowledge of the long-term care environment and regulations while NH staff posses a working knowledge of hospice/palliative care approaches and systems. This mutual understanding leads to respectful collaboration when each is cognizant of the other’s experiences and day-to-day challenges.

Nursing homes and hospice systems vary in their approach, design and structure which often leads to the myth or misunderstanding that the goals of care are different which may create unintentional competition or resentment. The misperception that hospice and NHs have differing goals is a barrier to quality partnerships as well as to access to hospice care. Fundamentally, hospices and NHs do have common goals for residents and their families. If you were to ask the question, “What do you want for your resident?” The common response is to provide comfort, compassion and dignity. Too often these areas of common goals are misunderstood or overlooked creating a barrier to collaborative care approaches or openness to mutually respectful partner relationships.

Optimal NH/hospice partnerships grow from understanding the value of common goals and collegial relationships. The misperception of differing goals prevents each partner from joining together toward common goals and instead creates a false belief that each partner is in opposition to the other, that their goals are different, and they therefore fail to see or understand the value each brings to the partnership. What does differ between NHs and hospices is their usual care approaches. The NH is focused on restorative and rehabilitative approaches and hospice on palliative care approaches. An essential fact is that most nurses and nursing assistants do not receive training in palliative care in their core academic programs and therefore lack skill sets necessary for
quality palliative care. These competencies must be learned outside the academic setting. Hospice programs provide this education to NH staff, helping to assure staff’s competency in palliative care.

**Communication, Communication, Communication! The Key to All Effective Relationships**

Quality relationships on any level, whether individuals or agencies are based on mutual understanding of each other's needs demonstrated through respectful, ongoing, effective communications. The following NH/hospice conversations demonstrate principles of respectful collaboration.

- Communicate commonalities – the resident’s needs as primary drivers of collaboration.
  - **Hospice to Nursing Home**: “I know your goal if for Mrs. G to be comfortable. Please share with me what your assessment of her comfort.”
  - **Nursing Home to Hospice**: “I realize you started narcotics to be given around the clock. This is not our usual procedure so please help me understand why it needs to be given that way.”

- Be open to learn from each other, respecting the different areas of expertise each brings.
  - **Hospice to Nursing Home**: “Mrs. H tells me her husband is not eating very well. Can you please help us understand your supportive feeding procedures so we can help when we are here?”
  - **Nursing Home to Hospice**: “Mr. R is very restless. We have done everything we can related to his physical comfort and he states that is not the problem. He seems most comfortable after your chaplain visits. Please help us understand his issues and how we can help between chaplain visits.”

- Approach your partnership as if you wanted to provide the best possible service not only to the resident and family but to each other.
  - **Hospice to Nursing Home**: “Thank you for taking the time to tell me about Mr. J. We are here to both serve and support Mr. J and his family as well as the staff in the nursing home. Please page us anytime you have a question so we can be of assistance in any way. We are available 24/7.”
• Nursing Home to Hospice: “I would like to keep you informed of Mrs. K changes as they seem to be happening quickly. What is the best way to do that?”

• Demonstrate knowledge, understanding and support of each others schedules, systems, regulations, and challenges.

  o Hospice to Nursing Home: “We realize when a patient is admitted to hospice that it triggers the need for an updated MDS. We can assist you in completing the MDS and documenting the unavoidable decline and need for palliative care. If you let us know when you’ll be meeting to care plan, we’ll schedule our visit at that time.”

  o Nursing Home to Hospice: “I realize that you schedule your visits with our residents but occasionally don’t get here on time because you are with another patient whose care is more imminent. If that happens, can you please call us and we’ll be sure to communicate that to the resident assuring them that you’ll be coming?”.

• Be proactive in anticipating and meeting each others needs.

  o Hospice to Nursing Home. “You mentioned that it is more difficult for your aides to attend to Mrs. T in the evening. Can we schedule a volunteer to be here during the evening meals so the aides can be with other residents that require help with feeding?”

  o Nursing Home to Hospice: “Since hospice is involved with several of our residents, would it be helpful if we schedule all of their care plan meetings on the same day so you don’t have to make multiple visits just for the meetings and can spend more time with residents?”

Resources for Success

The providers profiled in this research were ground breakers; many of the hospices were the earliest providers of hospice care in the NH and, in 1998/1999, many were also the most frequent providers of hospice care in the NH in the U.S. As such, these providers navigated the NH terrain without the benefit of guidelines or models. Today, some assistance exists (Henderson, Hanson & Reynolds, 2003; National Hospice and Palliative Care Organization, 2001; Pelovitz, 2002), and new, drafted federal regulations aim to more clearly document the requirements for provision of hospice care in NHs. Nonetheless, considering the resources devoted to collaborating by these large
hospices, one may question how and whether hospice care in NHs can be provided by hospice providers with fewer (educational) resources and staff. Through an ongoing Robert Wood Johnson funded project, we are studying how both large and smaller hospices provide care in NHs, and we are identifying key NH and hospice policies and practices common to successful NH/hospice partnerships (http://www.chcr.brown.edu/nhhsp/). Hospice in NHs is not equally prevalent within and across states (Miller and Mor, 2001), but the RWJ project will provide information on successful collaborators and their practices to enable greater prevalence by helping NHs and hospice to collaborate successfully.
The NH/hospice collaborative provides evidence that interprofessional and interorganizational collaborations can work. Clinicians with diverse backgrounds and training can successfully collaborate to provide end-of-life care for patients at the end of life. Needed for diverse professionals to provide optimal end-of-life care is a common understanding of the fundamental principles of quality end-of-life care and a respect for the systems of care in which both providers must operate. As portrayed, effective NH/hospice partnerships can 1) enhance quality end-of-life care for residents and their families; 2) maximize palliative care competency of all nursing facility staff responsible for providing direct care; 3) integrate the benefits of the two models of care — hospice and long-term care; and 4) assure effective documentation of palliative care when curative/restorative care is no longer the primary goal, and thus, decrease the perceived survey risk around palliative care patients.

Nursing homes and hospice systems vary greatly in their intent, design and structure. What drives nursing facilities and what drives hospice programs differ. Hospice staff brings expertise in palliative care, but may not have an understanding of the nursing facility environment or regulations. Likewise NH staff brings expertise in long-term care, but may not have an understanding of the specialty of palliative care. Hospice staff must have a working knowledge of the long-term care environment and systems while NH staff must have a working knowledge of hospice/palliative care approaches and systems for successful partnerships.

The best NH/hospice partnerships grow from understanding the value of collegial relationships. Staffs of hospices and NHs do have common goals for residents and their families; to provide comfort, compassion and dignity. Too often these areas of common goals are misunderstood or overlooked. The points listed below are considered key to effective NH/hospice collaborations; the principles they represent are applicable to the success of all interprofessional collaborations.

- Believe and act like you are both there for the same reasons.
- Keep the resident’s and their family’s needs and wishes paramount.
- Respect and utilize each other’s expertise.
- Educate each other and provide resources for ongoing learning.
• Determine what would be most helpful to each other and coordinate services around those needs (i.e., hospice volunteers to help with feeding in the evening hours when NH staff are most busy, NH scheduling dressing changes when hospice nurse visits).
• Avoid “hospice arrogance” – hospice staff have more training and expertise in palliative care but supportive relationships are not developed through arrogance.
• Role model the highest standards of care and service.
• Be available, be flexible, and be open to hearing the needs of staff.
• Coordinate care planning to the systems within the NH.
• Ask to be involved in care plan meetings.
• Support each other as valued members of the same team.
• Offer emotional and grief support to NH staff.
• Arrange memorial services in the NH for residents and staff.

We lack a good understanding of the level of quality of end-of-life palliative care now provided in NHs, especially in NHs without hospice collaborations and to Medicare SNF residents who are not now eligible for simultaneous receipt of reimbursed Medicare hospice care. Research, however, has suggested care is differential by hospice enrollment status (Miller, Gozalo & Mor, 2001; Miller, Mor & Teno, 2000; Miller, Mor, Wu et al., 2001), and possibly even by whether residents reside in NHs with or without hospice collaborations (Miller, Gozalo & Mor, 2001; Wu, Miller, Lapane & Gozalo, 2005).

While interprofessional collaborations to improve end-of-life care can be encouraged and strengthened by individual provider efforts, thoughtful government regulatory and reimbursement policy is crucial to the promotion of such collaborations and to the provision of equitable care across residents. Accountability for the provision of high-quality end-of-life care to our most vulnerable population, the frail elderly in NHs, is both the responsibility of providers and of insurers (i.e., Federal and state governments, others). Systems that create the right incentives and provide oversight to encourage high-quality end-of-life care are a necessity.
REFERENCES


