




**Improving  
Palliative Care  
IN Nursing Homes**

Center to  
Advance  
Palliative Care™

**capc**



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The Center to Advance Palliative Care (CAPC) is dedicated to increasing the number and quality of palliative care clinical services in hospitals and other health care settings across the country. A grant from the Fan Fox and Leslie R. Samuels Foundation (the Foundation) provided CAPC with the opportunity to extend its research into the nursing home setting and develop strategies for improving palliative care in nursing homes.

To accomplish the grant project's goals, a research team comprised of CAPC staff and expert consultants developed a survey tool and conducted in-depth interviews and site visits with experts and nursing home leaders across the United States. Research activities were guided by the framework of two previous efforts to standardize palliative care practices—the National Consensus Project for Quality Palliative Care that identified eight domains of quality palliative care, and the National Quality Forum's Hospice and Palliative Care Framework and articulation of 38 preferred practices for implementing palliative care programs.

The project's interviews and site visits revealed multiple barriers to providing quality palliative care in nursing homes. Organizational barriers include: poor transfers between nursing homes and hospitals and other sites of care; staff recruitment difficulties and high turnover; training and educational needs and challenges; and cultural differences. The charge to nursing homes to provide high quality care and at the same time maximize their residents' quality of life is set against the backdrop of fiscal constraints and strict regulatory oversight.

In response to these challenges, this report to the Foundation describes how palliative care—patient centered care focused on pain and other symptoms, superb communication, and safe and effective transitions—can offer solutions to the problems facing nursing home residents today. We conclude that sufficient knowledge of best practices exists to support development of palliative care in nursing homes. The report identifies promising models that are supportable from a business viewpoint, intersect with existing quality improvement and culture change efforts already being implemented in nursing homes, and are likely to improve the quality of care and quality of life for our nation's most fragile and vulnerable citizens.

## PURPOSE OF REPORT

The goal of providing the highest quality care for residents is the focus of the nursing home community. However, escalating service demands and limited resources constitute significant challenges to achieving this goal. This report summarizes the findings of an effort to assess the need for palliative care services in nursing homes and to identify successful models of palliative care service delivery in these settings.

## ACKNOWLEDGEMENTS

The Center to Advance Palliative Care is grateful to the Fan Fox and Leslie R. Samuels Foundation for its support of a planning project to explore how CAPC might help meet the needs of nursing homes as they work to provide palliative care to a growing population of frail elders who suffer from chronic complex illnesses.

The Center to Advance Palliative Care especially wishes to thank the many individuals who allowed us to interview and/or site visit their programs as part of this work. Your experience and insights were invaluable.

We also wish to recognize the individuals who contributed directly to the conceptualization and preparation of this report:

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# 1

## INTRODUCTION

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## A. PROJECT GOALS

In August 2006, the Fan Fox and Leslie R. Samuels Foundation (the Foundation) awarded the Center to Advance Palliative Care (CAPC) a planning grant to develop strategies for providing palliative care in nursing home settings. The purpose of the planning grant was three-fold:

- 1) Assess the need for palliative care in the nursing home setting;
- 2) Evaluate effective approaches to meeting the need; and
- 3) Develop a practical strategy for extending palliative care services to nursing home residents.

This report to the Foundation reviews the needs assessment conducted by project researchers and describes our findings. The need for extending palliative care services to nursing facilities is compelling, and the report includes suggestions for future initiatives in this area.

## B. PROJECT BACKGROUND: WHY PALLIATIVE CARE IN NURSING HOMES?

*By 2030 the number of people living in nursing facilities in the U.S. is expected to double, to over three million.*

It is a well known that the population of the United States is aging as the baby boomer generation reaches senior citizen status. Some experts project that the number of frail elderly will triple or quadruple in the next 30 years.<sup>1</sup> At the same time the number of informal and paid caregivers is decreasing, technical medical advances continue to increase life expectancies, and economic incentives and lack of bed capacity in acute care hospitals are forcing early discharge of the frail elderly and chronically ill.

Consequently, as the number of persons living with severe, debilitating illnesses increases over the coming decade, so too will the numbers living and dying in nursing homes, despite a widely held desire by elderly individuals and their families to avoid a nursing home environment.<sup>2</sup> To many individuals, nursing home admittance equates to institutionalization and is tantamount to abandonment. For nursing home residents, moving to a nursing home can mean living with a stranger as a roommate for perhaps the first time, dealing with a staff they don't know, and losing control of their life.

A growing number of nursing facility residents today are seriously ill or are actively dying. This dynamic influences several aspects of nursing home care:

- Untreated or under-treated pain in nursing homes is well documented;<sup>3</sup> half of the people living in nursing homes suffer from untreated pain.<sup>4</sup>
- Sixty-five percent of nursing home residents are functionally impaired and need help with three or more Activities of Daily Living (ADLs).
- A study conducted in 2000 revealed that at least one-third of nursing home residents in the U.S. suffer from malnutrition or dehydration (generally blamed on high turnover and inadequately trained staff).<sup>5</sup>

- Although 70 percent of Americans say they prefer to die at home, only 25 percent actually do so, with the remainder dying in an institution (50 percent in hospitals and 25 percent in nursing homes). The proportion of deaths in nursing homes is projected to rise to over 40 percent by 2030. The number of deaths in New York City nursing homes increased 66 percent over the past decade.<sup>6</sup>

Palliative care can relieve this suffering and support the best possible quality of life for nursing home residents and their families. There is a demonstrated need for the skills, approach and compassion of palliative care teams to ensure that nursing home residents fully understand their options, have their symptoms managed for optimum function and control their choices regarding quality of life. Says Rosalie Kane, Ph.D., Professor of Health and Quality Management at the University of Minnesota:

*“Because nursing homes are places to live, in addition to clinical settings, quality of life is salient. Health care needs might be met at the expense of drastically changing someone’s daily life and routines for the worse. The challenge is to pay attention to quality of life as an outcome in itself, and see how health care may be related to quality of life.”<sup>7</sup>*

While nursing homes are challenged by limited resources, overwhelmed frontline staff and beleaguered leadership, the case for improving palliative care practices in nursing homes is strong. Palliative care programs provide for the assessment and treatment of pain and other symptoms, help with patient-centered communication and decision making, and coordinate care across the continuum of settings. Over the past decade the principles of palliative care have changed the face of medicine, as palliative care values and philosophies are making their way into medical school classrooms, hospitals (including technology-focused ICUs), dialysis facilities, cancer centers, the Veterans Administration system and correctional institutions. By 2030, it is estimated that 40 percent of Americans will die in nursing homes. It is now time for nursing facilities to assure that their residents have ready access to all the domains of palliative care.

### **C. NATIONAL CONSENSUS PROJECT AND DOMAINS OF PALLIATIVE CARE**

*Palliative care is not restricted to end-of-life care, and is appropriate for any patient with a serious chronic illness, regardless of prognosis. Hospice is a form of palliative care specifically targeted to the dying—those with a prognosis of six months or less if the disease pursues its normal course.*

To standardize palliative care practices for the growing number of people with life-threatening or debilitating illnesses, five major palliative care organizations—American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, Hospice and Palliative Nurses Association, Last Acts Partnership and the National Hospice and Palliative Care Organization—came together to develop and present consensus clinical guidelines for quality palliative care services. *National Consensus Project Guidelines for Quality Palliative Care*, published in 2004, are intended to promote consistent, high quality

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care and guide the development and structure of both existing and new palliative care services. Because the ideal scenario is for people to receive palliative care services across the continuum of health care, these guidelines aim to promote consistency across a range of delivery settings. As such, they offer an appropriate framework for the research and findings of this project.

Known as the National Consensus Project (NCP), the palliative care organizations identified eight domains as the framework. Within these domains, the guidelines describe core precepts and structures of palliative care.

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#### Domains of quality palliative care

1. Structure and processes of care
  2. Physical aspects of care
  3. Psychological and psychiatric aspects of care
  4. Social aspects of care
  5. Spiritual, religious and existential aspects of care
  6. Cultural aspects of care
  7. Care of the imminently dying patient
  8. Ethical and legal aspects of care
- 

A second initiative, sponsored by the National Quality Forum (NQF), based its work on the NCP project, and used the NCP guidelines to develop a framework for assessing palliative care quality. *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*, published in 2007, describes 38 preferred practices for implementing palliative care programs (see Appendix A for listing of all practices; see accompanying Table for examples of application in nursing homes). The National Consensus Project recommends that the two documents be used together to guide the development of new palliative care programs and improve existing ones.

<sup>1</sup> [www.efmoody.com/longterm/nursingstatistics.html](http://www.efmoody.com/longterm/nursingstatistics.html)

<sup>2</sup> Teno, JM. "Now is the time to embrace nursing homes as a place of care for dying persons." *Innovations in End-of-Life Care*, 4(2), 2002. Also at [www.edc.org/lastacts](http://www.edc.org/lastacts).

<sup>3</sup> Teno, JM, Weitzen S, Wetle T, Mor V. "Persistent pain in nursing home residents." *Journal of the American Medical Association*, 285:2081, 2001.

<sup>4</sup> "Dying," *USA Today*, 2003.

<sup>5</sup> National Citizens' Coalition for Nursing Home Reform, 2000.

<sup>6</sup> [www.efmoody.com/longterm/nursingstatistics.html](http://www.efmoody.com/longterm/nursingstatistics.html)

<sup>7</sup> Hostetter, M. "Issue of the Month: Changing the Culture of Nursing Homes," *Quality Matters: Nursing Home Improvement, a Newsletter from The Commonwealth Fund*, January/February, 2007.

# 2

## METHODOLOGY

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The primary activity supported by this planning grant was an assessment of the need for palliative care in nursing homes and identification of potential interventions that would effectively meet this need. This assessment included an environmental scan of current palliative care services in nursing homes for gaps and opportunities.

In this section we describe our efforts to gather information about palliative care in nursing homes from three sources:

- a selected review of the relevant literature and resources available;
- 33 in-depth telephone interviews (most interviews included several participants); and
- three site visits.

Project staff retained three consultants with extensive experience in nursing home, hospice and palliative care policy and development to help guide the project:

- Amber Jones, M.Ed., a health care consultant who works with providers who are seeking to start or improve or extend palliative care and/or hospice services, served as the senior project consultant.
- Judy Peres, LCSW-C, Supporting Successful Transitions, joined the project team to provide nursing home policy expertise.
- Lynn Spragens, M.B.A., of Spragens & Associates, contributed financial expertise, as well as policy consultation, to the project.

## **A. SELECTED LITERATURE AND RESOURCE REVIEW**

Project staff and consultants first identified selective literature on palliative care in nursing homes and developed a resource and existing tool list. (See Appendix B: Selected Reference List, and Appendix C: Palliative Care in Nursing Homes Resources and Tools.) We searched traditional health literature databases (e.g., PubMed and Medline), limiting the search to articles based on research conducted in the United States and published in English between 2004 and 2007. From the body of articles identified, we selected 74 to guide our work that:

- focused on nursing homes and palliative care;
- provided descriptive data on nursing home quality issues; and
- addressed nursing homes and end-of-life care.

This search revealed that palliative care is not currently a specific area of focus in nursing homes. In addition, delivering palliative care in nursing homes fits into the larger nursing home quality initiative and is not a “one size fits all” undertaking. Palliative care discussions in the literature generally identified the need for:

- specialized programming;
- specialized staff training;
- designated leadership;
- communication across the continuum of care; and
- dedicated staffing.

## B. TELEPHONE INTERVIEWS AND SITE VISITS

### *Discussion Guides*

Drawing from the findings from the literature review and a Web resource search, project staff developed discussion guides for conducting the telephone surveys. The guides included semi-structured and open-ended questions, ideal for an environmental scan. The discussions covered a range of topics related to providing palliative care in nursing homes. Though individual interviews varied, the general discussion guide ensured that all key questions were addressed.

The open-ended questions provided opportunities to identify palliative care needs in nursing homes, explore new leads and related topics and allowed respondents the opportunity to fully discuss the issue of making palliative care available in nursing homes. Key discussion guide topics included:

- What are the needs of nursing home residents?
- What are the perceived challenges in delivering palliative care in nursing homes?
- What are the influences on nursing home practice?
- What are special or innovative nursing home programs or tools for delivering palliative care in nursing homes?

### *Interviews*

A key component of the environmental scan consisted of interviewing nursing home experts. These experts represented a wide range—from staff in the trenches to national opinion leaders—of perceptions of hospice and palliative care. Project staff conducted 31 in-depth telephone interviews:

- Nursing home staff and medical directors: 8 interviews
- National nursing home organizational leaders: 7 interviews
- Representatives of five CAPC Palliative Care Leadership Centers<sup>1</sup> with nursing home experience: 9 interviews
- Nursing home researchers: 7 interviews

### *Site Visits*

To complement the information gathered in the telephone surveys, project staff conducted three site visits at: Morningside House, in New York City; Hebrew Home of Greater Washington, in Rockville, Maryland; and Palliative Care Center of the Bluegrass, in Lexington, Kentucky. The goal for the site visits was to obtain a comprehensive view of

<sup>1</sup> CAPC supports six Palliative Care Leadership Centers: Fairview Health Services, Minneapolis, MN; Medical College of Wisconsin, Milwaukee, WI; Mount Carmel Health System, Columbus, OH; Palliative Care Center of the Bluegrass, Lexington, KY; University of California, San Francisco, San Francisco, CA; and VCU Massey Cancer Center, Richmond, VA.

factors that might influence palliative care in nursing homes. In particular, we wanted to look at successful models and consider factors that lead to a successful program. We also anticipated that the site visits could offer information on factors that might influence the delivery of palliative care, such as regulations, economic conditions and staffing.

Individuals and sites were selected to provide a representative sample of nursing homes—including geographic diversity, rural and urban centers and both large and small homes. With the interviews and site visits we hoped to determine nursing home perceptions of palliative care, as well as discover strategies that were working in the homes.

# 3

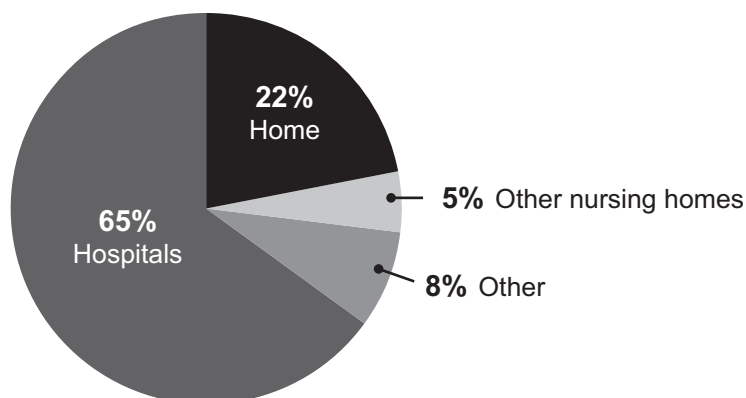
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## A. BACKGROUND

People enter nursing homes for a variety of reasons. Some may enter for a brief time when they leave the hospital because they need sub-acute care such as skilled nursing care, medical services and therapies. Others, however, enter nursing homes as a residential home option when they can no longer care for themselves. For these people the nursing home becomes both their residential home and their medical home. Nursing homes are generally defined as a broad range of personal, social and medical services that assist people who have functional or cognitive limitations in their ability to perform self-care and other activities necessary to live independently.

Nursing home residents come from:<sup>1</sup>



The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for residents and their families, regardless of the stage of the disease or the need for other therapies. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making and providing opportunities for personal growth. It can be delivered concurrently with life-prolonging interventions or as the main focus of care<sup>2</sup> (National Consensus Project in its report Clinical Practice Guidelines for Quality Palliative Care).

The palliative care needs of a nursing home vary by the characteristics of their patient population. Patients admitted for short term rehabilitation under Medicare reimbursement have traditional rehabilitative and medical needs and do not require all the features of a “residential home.” However, long-term residents who will live in the home until they die need a resident-centered home care approach. For these residents the challenges of “culture clash” between the traditional medical model and the home-like goals of culture change efforts in nursing homes are more pronounced.

To add to the tension between the medical model and the culture change movement in nursing homes, the demographics of nursing homes are changing. Survey interviews revealed that more nursing home residents present with chronic complex illnesses and

multiple medical problems requiring more sophisticated clinical interventions. Staff credentialing requirements and limited nursing availability make it difficult to keep pace with the increasing medical acuity. Furthermore, these residents with ongoing complex health conditions are living in nursing homes for several years. While the national average length of stay in nursing homes is 272 days (608 days for residents covered by Medicaid)<sup>3</sup>, one nursing home administrator interviewed for this project noted:

*“Our residents tend to be with us for a long time. It is not uncommon to have someone live here for seven to nine years—the average length of stay is 2½ years.”<sup>4</sup>*

Finally, these residents with multiple chronic conditions and increased illness levels undergo frequent transitions out of the nursing home, primarily to hospitals. In particular, persons nearing the final months of life have the highest potential for spending time in hospitals, nursing homes and hospice care. Hospitalizations and transfer to and from nursing homes routinely result in sub-optimal transitions, putting the resident at risk and frustrating staff in both settings. Residents often experience serious quality problems as a consequence of poor hand-offs and transitions, including medication errors, poor communication of new care plans, changing care teams, and transportation delays and discomforts. The quality of life and the quality of health care for frail, vulnerable elders with life limiting illness must be an integral part of nursing home care. Quality of care, quality of palliative care and quality of life, though closely related, are distinct elements in nursing homes. Improving the quality of each of these will require systematic long-term collaboration between the regulators, the provider community, the culture change movement and nursing home leadership at the local and national levels.

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The effort to integrate palliative care into all health care for persons with debilitating and life-threatening illnesses should help to ensure that:

1. Pain and symptom control, psychosocial distress, spiritual issues and practical needs are addressed with patient and family throughout the continuum of care.
2. Patients and families obtain the information they need in an ongoing and understandable manner, in order to grasp their condition and treatment options. Their values and goals are elicited over time; the benefits and burdens of treatment are regularly reassessed; and the decision-making process about the care plan is sensitive to changes in the patient’s condition.
3. Genuine coordination of care across settings is ensured through regular and high-quality communication between providers at times of transition or changing needs, and through effective continuity of care that utilizes the techniques of case management.
4. Both patient and family are prepared for the dying process and for death, when it is anticipated. Hospice options are explored, opportunities for personal growth are enhanced and bereavement support is available for the family.

— *Clinical Practice Guidelines for Quality Palliative Care*

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## B. ENVIRONMENTAL SCAN: PALLIATIVE CARE IN NURSING HOMES TODAY

As its first goal, the planning grant supported an assessment of gaps and opportunities to improve palliative care in nursing homes. The assessment revealed that while some components of palliative care are delivered in most nursing homes, few have formal palliative care programs, and leaders' perception of the quality of care they are delivering is often at odds with resident experience. Most nursing homes believe they offer good palliative care as part of their mission, even if the services are not identified as such ("good palliative care is good nursing home care,"<sup>5</sup> "good geriatric care is palliative care"<sup>6</sup>). Some acknowledged that they know little about palliative care, and some see palliative care solely as end-of-life care. One respondent equated palliative care to complimentary therapies, including massage, aromatherapy and music therapy. Others acknowledged that the increasing acuity of illness in their resident population is driving a corresponding increase in the need for palliative care services—and they see opportunities for growth in this area.

During the interviews several nursing homes stated they were "hungry" for educational materials for staff and for families of residents on palliative care, not realizing that palliative care training tools are available. In addition to the TIME Toolkit, other tools identified by best practice nursing home models were the MOLST (Medical Orders for Life-Sustaining Treatment) and POLST (Physician Orders for Life-Sustaining Treatment) tools, which translate resident goals and preferences into medical or physician orders. However, POLST and MOLST systems are dependent on state enabling legislation. Some nursing homes interviewed for the project use tools developed by a joint venture between the University of Pennsylvania School of Nursing and Genesis Elder Care (these include brochures, sample surveys, pain assessment tools and audits and training modules). Appendix C describes these tools and provides Web links.

Some nursing homes are developing their own tools, such as documents describing advance directives and standing orders that help manage common symptoms and drug administration challenges. For example, the Fundamental LTC Companies (a for-profit chain of 80 nursing homes) recognized the need for increased attention to palliative care and recently published a palliative care resource manual for use in all of its homes. A member of the Alliance for Quality Nursing Home Care and the American Health Care Association, Fundamental emphasizes the need for interdisciplinary care teams and palliative care in the homes. The parent company also offers to its members the Brown University TIME Toolkit (see Appendix C) online to help identify and assess needs of residents who would benefit from palliative care.

### 1. Why Improvement is Needed

The principles of palliative care intersect with good nursing home care. Most nursing homes surveyed for the project said that quality care is palliative care. As one researcher interviewed for the project observed:

*"Nursing homes have incredible experience in care of the dying," due to their "on-the-job training."*<sup>7</sup>

While several successful models have emerged from efforts to increase access to palliative care in nursing homes, these have not been systematically “packaged” for successful replication or adoption. Project interviews as well as multiple published studies reveal that most homes need better advance care planning and goals of care discussions, as well as improved pain and symptom management—two basic tenets of palliative care. Improvements in these critical areas, as well as other domains that address quality of care and psychosocial issues, face several organizational, regulatory and financial barriers.

## 2. Barriers to Improvement

### Organizational Barriers: *Transitions*

Transfers between hospitals and nursing homes, and the lack of consistency and medical errors they engender are acknowledged barriers to good palliative care. Poor transitions were a dominant theme in the project nursing home provider interviews. During the last year of life, nursing home residents often experience several disruptive and disorienting transfers.

Moving between nursing homes and hospitals increases patient stress and entails significant clinical risk, as there are few bridges to support continuity between the daily routines of nursing homes and hospitals. Good care within each setting is often “undone” through poor handoffs at transition. As palliative care becomes more available in hospitals, residents who benefited from palliative care services in the hospital experience disruption of relationship, care plans, and symptom management when discharged from the hospital to the nursing home setting. Conversely, when there is no palliative care team in the hospital, or when the team is not engaged in the patient’s care, the nursing home team is frustrated by the discontinuity introduced at the hospital.

There is quantitative evidence that patient safety is jeopardized during transitions of care. Medication errors are extremely common and pose a well-documented and significant threat to patients undergoing transitions.<sup>8</sup> When care is received in multiple settings patients often obtain medications from different prescribers. Clinicians rarely have complete information to adequately monitor a patient’s entire regimen, or to intervene to reduce discrepancies, duplications or errors. In one study hospitalized nursing home residents experienced three medication changes that led to an adverse drug event 20% of the time.<sup>9</sup> A survey conducted by the American Medical Directors Association found that 22% of transfers had no formal summary of information; legible summaries were available only 56% of the time; secondary diagnoses were missing in 30% of the transfers; test results were omitted in 31% to 67% of transfers; advance directives and code status were absent in 81% of transfers; and a legible phone number for the transferring physician was present in only 33% of transfers.<sup>10</sup> Quantitative studies consistently show that patients and their caregivers are unprepared for their roles in the next care setting, do not understand essential steps in the management of their condition and are unable to contact appropriate health care practitioners for guidance.<sup>11</sup>

Hospitals often have very little interaction with the nursing homes from which their patients are admitted. Says Sister Pauline, Administrator for the Teresian House in Albany, New York:

*“One of the problems with area hospitals is that they have a distorted view of who we are and the services we offer. They tend to pigeonhole nursing homes as resident warehouses. They do not visit to test these false assumptions.”*

Poor communication between systems and also with residents and their families often exacerbates the transfer problem:

*“It is not uncommon for a patient to arrive on our doorstep from a hospital without having been told or understood that they are going to a nursing home. This is not acceptable.”<sup>12</sup>*

Some transfers are plagued by poor communication resulting from misinterpretation of HIPAA privacy regulations which are perceived to preclude sharing of essential patient information between providers. Several survey respondents reported that residents returned from hospitals to their nursing homes with new pressure ulcers and/or medication errors. Others reported medication orders that were incomplete or inconsistent with medications available on nursing home approved formularies or with drugs the nursing home could access readily and/or deliver<sup>13</sup> (hospitals and nursing homes have different formularies, and the range of medications used differs).

Changes in physician roles in hospitals are also having an impact. One nursing home administrator explained:

*“In the past, the primary care physician provided continuity for residents when a hospital transfer was necessary. The physician would care for the resident here and would also care for the resident in the hospital setting. However, with the advent of hospitalists—all that has changed. The primary care physicians no longer offer services in the hospital—so there is no continuity of medical oversight. The hospitalists often have limited knowledge of the resident’s history, current medications and preferences and we receive little if any communication about the care offered to our resident in the in-patient setting.”<sup>14</sup>*

One nursing home administrator noted the problems associated with nursing home residents entering the hospital through the Emergency Department (ED) (Medicare will only pay for transports to the ED), and how difficult the ED setting is for a chronically confused resident. Another nursing home Medical Director recounts:

*“I have called the ED to let staff know we are sending a nursing home patient, and to try to communicate the circumstances. However, by the time our patient arrives and is evaluated, a shift change has occurred so the physician who manages her care is not the individual with whom I spoke. Given the emergent nature of their work, ED physicians almost never call a referring physician for patient information.”<sup>15</sup>*

Communication between nursing home physicians and hospital physicians is not common. Physicians practicing in nursing homes rarely have hospital privileges, and most physicians who have hospital privileges do not practice in nursing homes, a reality that contributes to cross-site communication problems.

Efforts to alleviate these transition failures are emerging rapidly. One option is the POLST (Physician Orders for Life-Sustaining Treatment) form (See Appendix C for detail). The POLST paradigm was pioneered in Oregon, and is now supported in several other states, some under a different name (such as New York's MOLST—Medical Orders for Life-Sustaining Treatment). The POLST form is a brightly colored medical order sheet placed in the front of the medical record and transferred with the patient whenever they move between settings. A physician or other health professional writes orders on this form that indicate what types of life-sustaining treatment a patient wants. The form follows a patient between care settings—from home to hospital to nursing home. At home the original form can be placed on the refrigerator where emergency responders can find it. In a hospital or nursing home the form can be kept on the front of the patient/resident's chart. The POLST form is designed to express the individual's preferences for goals of care and associated levels of treatment and can indicate either all life sustaining measures, including resuscitation attempts, or can be used to limit those interventions that the individual does not want. The goal is to ensure that the patient or resident receives the level of care desired. In addition, use of the POLST form helps facilitate discussions between the patient or resident and their health care provider and informs all providers subsequently involved in the individual's care about the existing goals and plan of care and medications.

Other approaches to improving care transitions include the United Hospital Fund's campaign, "Campaign for Family Caregivers," which is based on the premise that a family caregiver is often the only person who knows the patient intimately and has followed the course of treatment from the beginning, and across care settings. The United Hospital Fund proposes that transition protocols could be adapted to include family caregivers specifically, as they have critical information about a patient's care history and medications.<sup>16</sup>

Eric Coleman, M.D., an Associate Professor of Medicine at the University of Colorado Health Sciences Center, designed a tool called the Care Transitions Measure (see Appendix C for Web link) to measure care transition quality and performance. It not only improves the quality of transitions, but also enables patients to become more engaged in their own care. CAPC is in the process of developing its own "Transition Management Curriculum Module" for its Palliative Care Leadership Center curriculum.

Despite these and other efforts, the variation and inconsistency caused by disruptive patient transfers between hospitals and nursing homes continue to be stressful and risky for frail nursing home residents—a "horrid transitional problem."<sup>17</sup> Even in those communities where hospitals have adopted palliative care programs and provide good palliative care, discontinuities remain the norm. A nursing home resident may be discharged from the hospital in stable condition with their pain managed and symptoms controlled, and with clarity among family members regarding goals of care. A number of circumstances can "undo" the patient's progress: the lack of outpatient follow-up capability

by the palliative care team; the lack of a personal relationship between hospital and nursing home personnel; or poor handoffs through discharge planning, the discharging physician, or on the receiving side from the nursing home Medical Director and/or admissions staff.

### **Organizational Barriers: *Staffing***

Inadequate staffing levels, the absence of continuous education, and inconsistency are widely acknowledged problems in nursing homes. The nursing home field is plagued with labor shortages, along with difficulties in worker retention, supervision and training opportunities. Common causes of high staff turnover include the difficulty of the work, relatively meager pay and benefits, a lack of respect for staff roles, frustration with the quality of care, and demanding paperwork and regulatory requirements.

The Federal Nursing Home Reform Act, or OBRA 87, created a set of national minimum standards of care and rights for people living in certified nursing homes. The regulations established with OBRA 87 are vague, requiring homes to have “sufficient staff” without addressing any minimum ratios.<sup>18</sup> The Centers for Medicare and Medicaid Services (CMS) staffing studies estimate that 90% of nursing homes are understaffed. Turnover at all levels—from frontline to leadership—is high, exceeding 100% annually in some homes.<sup>19</sup> “Too few staff and too little time” was a theme echoed in many of our interviews.<sup>20</sup>

Medical Directors can have a significant influence on quality of palliative care, and this field is under stress due to the shortage of geriatricians and of physicians with palliative care training. Many Medical Directors are not in the facility on a daily basis and work on a very part-time basis for the nursing facility. In small homes, in particular, this is a challenge to quality. As one researcher interviewed for the project observed:

*“When there is greater physician time and nurse practitioner time... we see greater quality of care for the residents.”<sup>21</sup>*

This researcher also believes that hospitalizations can be prevented with the presence of a physician or nurse practitioner in the home.

The scarcity of physicians with strong geriatrics skills and palliative care training creates an incentive for nursing homes to hire their own nurse practitioners or to affiliate more formally with local palliative care experts or hospice teams. In addition to providing much needed access to on-site care, these palliative care and hospice experts in the community can develop collaborative relationships with the Medical Directors and nursing staff, and improve their skills and awareness of palliative care needs.

Plans for change should recognize the stress and challenge of staffing shortages, which create resistance to any new tasks and documentation and mean that training has a short-term effect and must be repeated. Discussions of turnover should also differentiate among the different critical players affecting nursing home care:

- Medical directors;
- Directors of nursing;
- Nursing assistants;
- MDS (Minimum Data Set) coordinators;
- Administrators/leaders; and
- Other staff influencing culture and care.

### **Organizational Barriers: *Training and Education***

Training can be successfully used to improve the availability and delivery of palliative care services. For example, survey and site visitor respondents report a growing need for training in pain and symptom management. Nursing home staff, providers, residents and families requested orientation about the differences between palliative care and hospice and about how best to encourage and support improved advance care planning. Education in nursing homes, particularly for direct-care staff, currently focuses on clinical skills and direct patient care tasks. Our surveys indicated that entry level nurses and nursing aides, who provide the bulk of patient care, also need training in symptom assessment and treatment, communication, decision making and the problem-solving skills required to effectively interact with and deliver quality care to residents. Involving hands-on providers in care planning promotes better understanding of resident needs.<sup>22</sup> One researcher interviewed for this project stated that she views Certified Nurse Assistant (CNA) participation at care planning meetings a mark of a good home.<sup>23</sup>

Respondents to the project survey generally agreed that the key to providing quality care (and quality palliative care) is in the recruitment, retention and training of all nursing home staff, particularly frontline workers. Certified Nursing Assistants (CNAs), who assist residents with activities of daily living and provide bedside care under the supervision of a Licensed Practical Nurse (LPN) or Registered Nurse (RN), provide 80% of direct care in nursing homes. A comprehensive curriculum designed to enhance palliative care skills of CNAs in nursing homes is available through the Hospice and Palliative Nurses Association (see Appendix C).

Conducting effective goals of care discussions with residents and families requires both skill and time on the part of all nursing home staff to address these personal and sensitive issues. Several palliative care training resources are available that can be adapted to nursing homes: including the End-of-Life Nursing Education Consortium (ELNEC) geriatric course for licensed nursing staff who work in long-term care facilities; training seminars offered by the American Academy of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nursing Association (HPNA); and a geriatric nursing curriculum developed by The John A. Hartford Foundation that focuses on best nursing practices in care for older adults (see Appendix C for these and others).



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### Components of typical palliative care educational programs:

- History and philosophy of hospice and palliative care
  - Pain management
  - Symptom management
  - Decision making
  - Communication
  - Cultural issues
  - Loss, grief and bereavement
  - Spiritual care
  - Ethical and legal issues
  - Care when death is imminent
  - Caregiver self-care
  - Economic issues
  - Professional issues
- 

Some nursing homes reach out to local palliative care experts to develop in-house training programs. Annie Durkin, N.P., the palliative care director at Potomac Valley Nursing and Wellness in Rockville, Maryland, explained that their nursing home “jump started” their palliative care program with direct training from Martha Henderson, MSN, DrMin., and Laura Hanson, MPH, MD, authors of *Improving Nursing Home Care of the Dying: A Training Manual for Nursing Home Staff* (see Appendix C for Web link and description). Durkin continues to use the training manual for all staff.

To be successful in improving palliative care in the face of workforce challenges, training programs should include the following considerations:

- Training programs can’t take frontline staff away from their jobs—given the shortage, traveling to training or blocking full days is a prohibitive barrier.
- Portions of the training need to be low cost and accessible for frequent training and reinforcement—to continuously offer to new hires, and to reinforce principles in “bite sized” pieces.
- Leadership (including governing boards, CEOs, administrators and Directors of Nursing) need to fully embrace the goals and methods of the training. Implementation of training concepts requires support from senior staff.
- Didactic approaches appear to have limited effect, while experiential training, role play, case studies and video support are viewed as more effective.

Training opportunities noted above address several of these issues by offering educational modules through CD-ROM formats and online courses supplemented with PowerPoint presentations and video clips. However, several nursing homes interviewed for this project have no access to the computer technology needed for these educational offerings.

## Organizational Barriers: *Cultural Differences*

Some nursing homes experience cultural barriers to delivering and providing palliative care as the aging population of the United States is becoming more racially and ethnically diverse. As of March 2000, the estimated foreign-born population of the U.S. was 28.4 million.<sup>24</sup> In 2002, 17.24% of the 65+ population in the U.S. were minorities (8.1% were African American, 5.5% were of Hispanic origin, 2.7% were Asian or Pacific Islanders, 1% were American Indian and 0.5% identified themselves as two or more races).<sup>25</sup> Despite the increase in recent decades in immigrant and minority populations, health care workers are still largely unfamiliar with the varying needs of a multicultural population. Many aging minorities have attitudes, preferences and expectations of the health care system that are different than those encountered among white individuals and incorrect assumptions can lead to mistrust of health care providers across the continuum of care. Populations often misunderstood in the health care setting include Muslim, Jewish, Hispanic and Asian patients, as well as disabled and rural residents and patients of diverse sexual orientations.<sup>26</sup> Nursing home residents from diverse backgrounds may have specific customs and beliefs about dietary regimens, processes of medical decision-making and the role of family in such decisions, as well as specific rituals and expectations surrounding the process of dying and the death and its aftermath. Documented differences in the aging of minority populations as compared to white Americans also deserve attention.<sup>27</sup>

Nursing homes with residents from diverse ethnic backgrounds need to develop culturally appropriate resident assessments so that each resident and his or her family are evaluated regarding how strictly they observe their culture and religious rituals. Ideally, preferred language should be discussed and interpreters provided if needed. Although more work in the area of cultural competency education needs to be done, some educational resources that could be adapted to nursing homes are available through the Commonwealth Fund, The John A. Hartford Foundation Institute for Geriatric Nursing, National Hospice and Palliative Care Organization and Physicians for Human Rights (see Appendix C for detail). The Commonwealth Fund recently released a series of reports examining the role of cultural competency in quality improvement initiatives, *Taking Cultural Competency from Theory to Action*.<sup>28</sup> According to this report, a successful cultural competency effort requires:

- Community leadership and feedback;
- Integration into all aspects of care;
- Reliance on measurable and sustainable changes;
- Executive commitment;
- A solid business case for initiatives; and
- Continual staff training.

Not only do nursing homes need to develop cultural competencies among their staff serving minority elders, homes with concentrations of workers from minority and diverse ethnic backgrounds need to identify both the specific beliefs of staff and ways to align those perspectives with organizational expectations. For example, staff from diverse



backgrounds, including Filipinos, African Americans, Africans and Native Americans, may have different perspectives about which services and conversations are appropriate for nursing home residents.

## Regulatory Barriers

*“Palliative care services are not being put to practical use. If an intervention or interventions are not specifically related to a survey or to reimbursement—it is just not on the radar screen of administrators.”<sup>29</sup>*

Nursing homes are subject to stringent regulation and oversight by several federal and state agencies. While the intent of regulation is to protect the safety of a vulnerable population, the continuous need to interpret and respond to rules and requirements that may appear to be in conflict with individual resident circumstances greatly complicates and distracts from the ability to provide quality care and services. A tangle of coverage, financing, regulation and oversight rules interferes with the delivery of palliative care in many homes. For example, nursing homes fear that the inevitable weight loss and dehydration associated with the natural process of dying may be perceived as regulatory failure. This results in increased transfer of dying residents to hospitals, and enormous pressure to use artificial nutrition and hydration among the dying, to avoid regulatory censure. Some nursing home administrators erroneously believe that CMS’ mandatory tool to assess residents, the Minimum Data Set (MDS), makes hospice and palliative care services less feasible.

The Resident Assessment Instrument/Minimum Data Set (RAI/MDS) instrument may actually help facilitate palliative care in nursing homes if it is used with precision. Four treatment goals are identified in the RAI/MDS User’s Manual Version 2.0: rehabilitation, maintenance, prevention and palliative care. Palliative care can be the overall goal for a nursing home resident, but specific interventions to maintain the resident and prevent suffering need to be documented. Palliative care goals, as with all care planning goals, require ongoing assessment and careful documentation about the resident’s strengths, needs and problems. With appropriate documentation, the RAI/MDS manual is clear that proper care does not mean that the nursing home must continue to provide rehabilitation or restorative interventions for dying residents, nor is it necessary to force artificial feeding or hospital transfers on such residents. Providing quality palliative care is actually supported and guided by the MDS, as long as the nursing home correctly identifies palliative care as the primary treatment goal.

Many believe that revising restrictive regulations would help nursing homes do the right thing. One nursing home administrator who participated in the project survey, however, had this view to offer:

*“Homes that are not doing well will blame the survey system... but we know that homes that are ‘resident-focused’ do better on the survey system... documentation is key... as long as the home can prove what its doing is resident-centered and the resident’s choice... the survey system should not be a problem.”<sup>30</sup>*

State involvement in Medicaid and variability in policy state-by-state further complicate the regulatory barriers to providing good palliative care in nursing homes. Several states have tried to introduce legislation to improve wages to direct-care workers by establishing a requirement that states incorporate 100% of labor costs for recruiting, training, retaining and compensating qualified staff as part of their Medicaid payment rates, with a mechanism to incorporate cost-of-living increases. Many of these proposals have either failed or were too modest in scope. Change in the federal statute is needed to ensure sufficient Medicaid funding.

Unnecessary transfers from nursing homes to hospitals greatly disrupt the continuity of care for frail elders. However, reimbursement levels and requirements can affect transfers. If nursing homes lack the staffing needed to care for elders during acute episodes of illness, a hospital transfer is perceived as the only option. There are also Medicare structural financial incentives to transfer a nursing home resident to a hospital. After a three-day hospital stay some residents may once again be eligible for a higher nursing home Medicare reimbursement rate.

As part of the original enactment of Medicare in 1965, Congress required that a beneficiary have at least a three-day hospital stay to be eligible for the “extended care,” or Skilled Nursing Facility (SNF), benefit. While this arbitrary threshold requirement may have been logical 42 years ago, it does not make sense today. Technological advances and the creation of alternate sites to receive care formerly provided only in a hospital setting have rendered this requirement unnecessary. A hospital placement that is driven by a desire to qualify for the higher reimbursement associated with the Medicare ‘skilled’ benefit is not in the beneficiary’s best interest and is wasteful to the system.

Title XVIII of the Social Security Act could be amended to eliminate the three-day hospital stay requirement as a precondition to receiving the Medicare SNF benefit. The fact that many Medicare Advantage plans have found the elimination of the three-day hospital stay to be cost effective is evidence that its appeal as a condition of Medicare Part A coverage would have favorable consequences for beneficiaries and for the Medicare system.

Project interviews reinforced the perspective that the rules complicate implementation of good palliative care, but that this can be overcome by better and more accurate understanding of the regulatory requirements, education and documentation. Survey and site visit respondents suggest that many beliefs held by nursing homes regarding what is allowed or discouraged, or might introduce risk, are based on misperceptions and flawed information. This heavily influences nursing home leaders’ perceptions of safety vs. risk as they consider implementation of care plans for seriously ill, symptomatic or dying residents as well as roles and payment considerations related to hospice election. Palliative services are not restricted to residents at the end-of-life, nor should palliative care eligibility be defined in terms of a prognosis, but instead should be available to any resident who needs these services (attention to pain and symptoms; support for clarifying goals of care and a care plan concordant with such goals; and expert transition management across care settings. In contrast eligibility for the Medicare Hospice Benefit requires (by federal statute) that the resident be certified by two physicians as having a

prognosis of 6 months or less if the disease follows its normal course, and that the resident (or surrogate) agrees in writing to relinquish regular Medicare insurance coverage in return for access to hospice care. The need to clarify these important differences between palliative and hospice care was a recurring theme in the project interviews.

## Financial Barriers

Nursing home costs have more than doubled in the last decades due in part to a change in the acuity of residents. Individuals with lighter care needs now enter assisted living facilities and other community settings, and the sicker residents with no alternative other than nursing home require a higher intensity of care. In addition to the rising acuity factor, the burden of paying for nursing home care is a growing concern. Few individuals can afford to purchase nursing home care out-of-pocket; the cost for a year in a nursing home in the 10 most expensive areas of the country<sup>1</sup> is \$80,000 or more.<sup>31</sup> Long-term care insurance currently covers few individuals, and direct Medicare coverage for nursing homes is limited to the brief “skilled” rehabilitative/restorative benefit after a 3-day hospital stay. Staff vacancies and turnover contribute to rising cost, contributing an estimated \$4 billion a year<sup>32</sup> in nursing home expenses.

Medicare’s nursing home reimbursement emphasizes rehabilitation and restoration rather than palliation (such as paying for tube feeding rather than the more labor intensive staffing option of supporting and spoon-feeding a patient who has made a decision to discontinue the tube feeding). As one organizational leader stated in her interview:

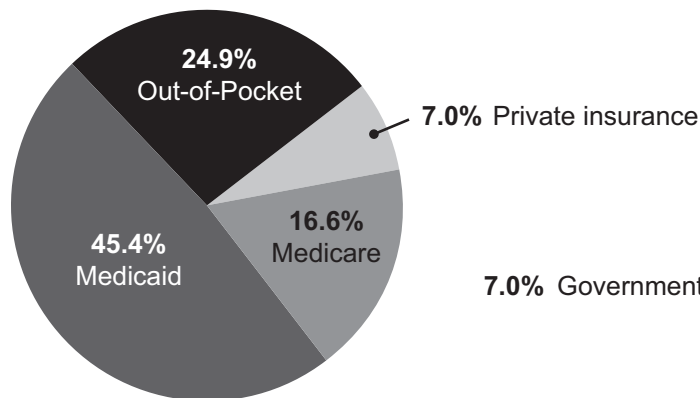
*“Despite the growing demand for long-term care, the existing financial mechanisms for Medicare and Medicaid are intertwined and increasingly dysfunctional.”<sup>33</sup>*

Declining Medicaid reimbursements, increasing percentages of long stay residents on Medicaid, and escalating cost cause nursing homes in most states to struggle daily with financial challenges. In 2000, five of the nation’s 10 largest nursing home chains filed for bankruptcy (accounting for 10% of all homes).<sup>34</sup> Those that do not struggle are typically affiliated with other lines of business or focus solely on more highly reimbursed Medicare short stay or private pay residents.

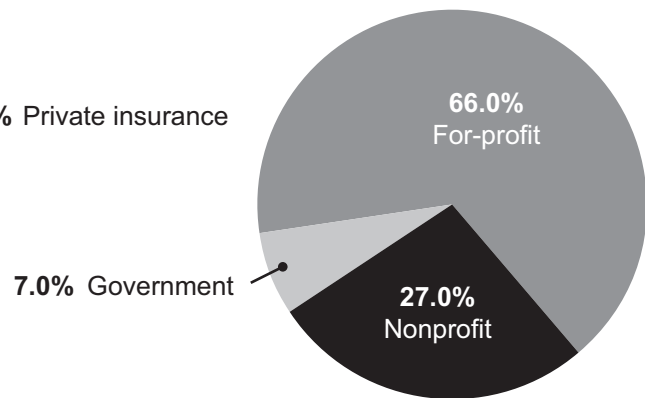
The tight financial constraints of nursing home management provide challenges for delivering palliative care. Many homes know what they need to do to improve the quality of life and care for their residents, but don’t have the necessary resources for service enhancement. Many nursing homes live in a management reality that focuses on current year performance; investment for long-term gains is not viewed as feasible. Successful strategies need to be very low cost and show virtually immediate gains in areas with financial impact: staff retention or effectiveness; supply costs or food costs; or revenue generation either through payer mix, higher occupancy or supplemental sources.

<sup>1</sup> Alaska, New York City metro area, Connecticut, New York state (outside NYC), District of Columbia, Hawaii, Massachusetts (outside Boston), Boston metro area, New Jersey, Philadelphia metro area

### Nursing home reimbursement in the United States:



### Nursing home ownership in the United States:<sup>35</sup>



Given these constraints and the financial landscape of the nursing home environment, it is often difficult for nursing home leadership to even consider developing a business model for a palliative care team as a stand-alone enterprise.

The nursing home palliative care innovators interviewed for this project tended to have certain characteristics:

- Their leadership has tenure, and therefore authority and power to make long-term investments.
- They operate within large organizations that have the ability to cross subsidize or invest in change.
- They shared the perspective that investing in these services helped their overall quality sufficiently to justify time and expense.

Payer mix can directly affect care. Despite the reality that most nursing home resident stays are funded by Medicaid (see reimbursement breakdown above), the National Senior Citizens Law Center states that nursing homes discriminate against Medicaid residents in favor of private pay residents. Medicaid residents may be relegated to a separate wing, be subject to eviction or receive inferior food and services.<sup>36</sup> In addition, a 2002 Government Accountability Office (GAO) report found that Medicaid's share of patients in a nursing home influenced the overall margin. The higher the share of Medicaid patient days in a home, the lower its total margin.

Misinformation about payer sources for palliative care emerged as a consistent theme in the provider surveys:

*"I know of no source(s) of revenue for palliative care per se."<sup>37</sup>*

This administrator thought the only payment source for palliative care consultation is

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private payment from the patient and/or family, was surprised to learn that palliative care physicians and nurse practitioners can bill Medicare Part B fee for service (if the consultation is requested by a nursing home attending physician), and that other insurers have negotiated payments. As a result, of these misperceptions, it is often the case that the only time a palliative care consultation is offered in a nursing home is to evaluate if or when the resident is hospice-appropriate.

To the extent that palliative care services bring provider resources that “extend” and support the staff at no cost to the facility, or increase accuracy of documentation (which could increase reimbursement based on patient acuity), or decrease costs of bed-holds or other very concrete challenges, these services will be very welcome. Two organizations we discuss in this report as models of “best practice” in nursing homes—Palliative Center of the Bluegrass and Four Seasons Hospice and Palliative Care—are leading examples of this practice.

### C. STRATEGIES FOR IMPROVEMENT: MODELS OF BEST PRACTICE

The second goal of the planning grant was to evaluate effective approaches for meeting the need for palliative care in nursing homes. Survey interviews and site visits gave project researchers insight into the current status of palliative care services in nursing homes, and revealed several best practices appropriate for replication through technical assistance, as well as opportunities for additional improvements. Research and conclusions were conducted against the backdrop of the Clinical Practice Guidelines articulated by the National Consensus Project for Quality Palliative Care (NCP) and the work of the National Quality Forum Framework to establish preferred practices for palliative care. The preferred practices articulated by the National Quality Forum reflect many of the mandated standards of care set forth in the OBRA 87 guidelines. Applying the preferred practices in nursing homes helps homes fulfill their mandate to provide resident-centered care.

Despite the barriers, there are opportunities to improve palliative care for nursing homes residents. What is the best way to introduce palliative care into nursing homes today? Every state and every community is different, and one model will not serve all nursing home needs. Several programs rely on external partnerships to sustain palliative care programs in their homes. Others build palliative care services from within. Project interviews yielded two key elements for maintaining these successful partnerships—**leadership** and **communication**. Effective, strong, caring leadership with a quality vision can sustain a culture of excellence. A commitment to excellence must be communicated to and understood by all staff throughout the home.

Based on the research, we identified four different models designed to integrate preferred practices for palliative and hospice care for nursing home residents:

#### 1. Palliative Care Consult Service

Palliative care providers who are not employed by the nursing home provide and bill for consultative services to residents as requested by the nursing home Medical Director, the

patient's attending physician or the nursing home Director of Nursing.

## **2. Hospice-based Palliative Care Consult Service**

Professional staff employed by a local hospice provide non-hospice palliative care consultative services as requested by the nursing home Medical Director, the patient's attending physician or the nursing home Director of Nursing.

## **3. Nursing Home Services Integrated Palliative Care**

Many nursing homes have embraced quality initiatives to improve patient and facility outcomes. While these efforts may not be defined as palliative care initiatives per se, they often incorporate one or more of the domains of care referenced in the National Quality Forum's Preferred Practices for Palliative Care and Hospice Quality (e.g. pain and symptom management). In the Nursing Home Services Integrated Palliative Care model, staff who provide these services may be employed directly by the nursing home. Alternatively, the care of individual residents in the nursing home may be managed under the direction of Evercare, a managed care insurance program which employs nurse practitioners to provide on-site services.

## **4. Hospice Care**

Hospice-eligible nursing home residents receive specialized end-of-life palliative care services from contracted hospice providers.

The following is a discussion of the four models, along with their strengths and weaknesses. Each model description includes at least one example, with the exception of Hospice Care, which is well-established and well-known. The model discussions conclude with "lessons learned" which may help guide nursing homes seeking to replicate these approaches.

It is important to note that the project researchers found that many exemplar programs received grant funding to design initial programs or interventions. However, grant funding is time-limited so most of these providers found it necessary to develop a well-defined business plan as the basis for growing and sustaining palliative care initiatives.

## **1. Palliative Care Consult Service Model**

This model brings outside palliative care consultative services into the nursing home. In addition to providing expert opinions as requested, the consultant may provide clinical care as requested by the referring physician, the Medical Director or the Director of

<sup>ii</sup> [http://www.hospicebg.com/programs\\_palliative.html](http://www.hospicebg.com/programs_palliative.html)

<sup>iii</sup> The Bluegrass Palliative Care Center is affiliated with the larger Hospice of the Bluegrass program that provides multiple services to over 800 residents in 23 central, southeastern and northern Kentucky counties. Hospice of the Bluegrass is also the parent organization. The two organizations represent two distinctly different models. The Palliative Care Center provides palliative care consultation services only. Hospice of the Bluegrass provides typical hospice-based palliative care.



Nursing. Consultants may also participate in staff education on palliative care topics.

### ***Palliative Care Center of the Bluegrass***

Palliative Care Center of the Bluegrass<sup>II</sup> is a separately incorporated entity dedicated to the provision of palliative care services. A model program, the Palliative Care Center of the Bluegrass is the host organization for the Palliative Care Leadership Center (PCLC) of the Bluegrass, one of six CAPC PCLC leadership centers across the country. The Palliative Care Center of the Bluegrass was one of three site visit locations for this project.<sup>III</sup>

*Program Description:* The Palliative Care Center provides consultation services in many different nursing homes. In this model the palliative care team serves as a consultant—the consultative services are provided by nurse practitioners backed up by physicians (a physician practice is required for set-up). Consultations are provided in response to a request from the attending physician, the Medical Director or the Director of Nursing. Requests focus on pain and symptom management issues, advance care planning, family communication and transition to hospice as appropriate. The relationship to the resident is generally limited to the issues and symptoms specific to the consultative request. Consultants also participate in staff training on palliative care topics. Resident eligibility for a consultation is determined by the referral source(s).

These consulting services are offered to many nursing homes in the Lexington, Kentucky area. An in-depth alliance with one of the nursing home partners helped to create a business plan by developing outcome measures, defining the responsibilities of each partner and shaping a budget. The primary goal of this project was to create a consultative model that would integrate palliative care within the philosophy of the nursing home. Subsequently, additional nursing homes have elected to invite on-site palliative care interventions.

*Results:* The nursing homes using the Bluegrass Palliative Care Consultation Service report high patient satisfaction, fewer emergency room transfers, better staff retention and improved patient symptom management, which make nursing home staff feel better about the care they are providing. Program leadership believes that its model would be easy to replicate, as long as nurse practitioners with both palliative care and nursing home experience are available.<sup>38</sup> Another noted element for a successful partnership is consistent attention to relationship-building between the practitioner and the nursing home Medical Director. A downside to the program is found in hospital transfers. Because the relationship with the nursing home resident is consultative only, it is common for transfers to occur without the consultant's knowledge. As a result, continuity of the palliative care approach to services in the hospital is often problematic.

Staff at Palliative Care Center of the Bluegrass provided the following 2006 statistics for their palliative care program:

Total new consults in 13 nursing homes: 299

Patient visits: 1,091

(1.25 FTE Palliative Care NP and prn MD)

Patients transitioned to hospice: 30%

Of the patients who transitioned to hospice:

58% received hospice care at the nursing home  
with an average hospice length of stay of: 66 days

42% were transferred to the hospice inpatient  
unit with an average length of stay of: 8.5 days

*Financial Viability:* Medicare and Medicaid payers and many private insurers directly reimburse for MD and NP consulting services, including those for residents who are accessing their Medicare Part A Skilled Nursing Facility benefit. Palliative care programs using this model have found that it is cost effective to send a nurse practitioner consultant to nursing homes where there is a cluster of patients needing consultation. Part B Medicare billing revenue covers the cost of personnel, if the travel time is short, and several consults are provided. This model brings expertise into the building that is of assistance to the nursing home staff, without a cost to the nursing home. The current reimbursement model for Part B billing does not cover the full cost of an interdisciplinary team, which is why the Palliative Care Center of the Bluegrass sends a nurse practitioner, who then works with the existing nursing home social work and medical staff. The Palliative Care Center of the Bluegrass nursing home practice is able to generate a modest excess of revenue over expense by clearly defining the parameters of care as primarily consultative and not as a full-time care management model. Further, consultants are expected to document and bill their services efficiently and effectively.

*Lessons Learned from the Bluegrass Palliative Care Center:*

- It is helpful to launch the palliative care consultative services with the assistance of a champion, well-known in the community. This leader is often a physician. Outreach may include promotional materials and/or formal or informal presentations to key publics.
- The initial presentation to would-be partners should clearly enumerate the benefits the nursing home will realize from the consultative services.
- The consultation service model grows physician-by-physician. In this model, an attending physician must write an order for a palliative care consult.
- The nurse practitioner role is essential and rapidly becoming a standard of practice in nursing home settings. Ideally, nurse practitioner palliative care consultants working in these setting have both nursing home and palliative care expertise.
- It is important to detail the partnership for attending physicians, the facility Medical Director and the palliative care providers. It may be helpful to create a fact sheet for referring physicians describing the role of the consultant and demonstrating how billing for the services of both the attending and consulting physician or nurse practitioner should occur.
- Nursing home staff is frequently over-extended. For this reason, consultants working in this setting must connect with key personnel and become as self-reliant in the setting as possible.



- Each nursing home is unique and requires an approach and a set of services designed to meet its specific needs and preferences.
- The palliative care consultant is expected to be the clinical expert in pain and symptom management. Good outcomes in these areas will benefit residents and families and will contribute to the good outcomes each home strives to deliver.
- Nursing home staff characterizes the ‘good consultant’ as the one who is available for and responsive to staff questions.
- Goals of care discussions are time-consuming and may be difficult for nursing home staff. The palliative care consultant who demonstrates expertise in this area is likely to realize increased referrals.
- Nursing homes must comply with MDS documentation requirements. The palliative care consultant progress notes should be written accordingly.
- Palliative care is a relatively recent specialty. In addition to familiarizing nursing home staff and attending physicians about palliative care, educating residents and families is a priority.

## 2. Hospice-based Palliative Care Consult Service

This model brings hospice staff to the nursing home to provide non-hospice palliative care consultation services. Consistent with the hospice philosophy, the services of an interdisciplinary team are available and are provided to residents receiving palliative care consultations on an as-needed basis. Consultations may be requested by the Medical Director, the attending physician and/or the Director of Nursing. Requests for service are often on behalf of residents who are likely to need hospice services as a consequence of the current illness.

### *Four Seasons Hospice and Palliative Care*

Located in Flat Rock, North Carolina, Four Seasons Hospice and Palliative Care,<sup>IV</sup> is an innovative nonprofit agency that provides comprehensive services for residents identified as “hospice-eligible” (identified as having a limited life expectancy) and for those identified as “palliative care” residents dealing with serious chronic illness.

*Program Description:* Over the years, the organization received grants from the Duke Endowment to expand palliative care services with hospital partners and to develop innovative ways to serve nursing homes. The primary provider of both hospice and palliative care services in Henderson County, Four Seasons Hospice and Palliative Care now has contracts with both hospitals in the area, every nursing home and most assisted living and group homes in the county. It also supports its own inpatient hospice facility. These relationships allow the organization to follow residents from setting to setting, providing consis-

<sup>IV</sup> <http://www.nchospice.com/>

tency across the care continuum, an important key to its successful delivery of services.

*Results:* Four Seasons tracks its interventions, and reports positive results from the services it provides in nursing homes. Four Seasons staff provided the following statistics for its palliative care consults in 2006:

- Total new consults in 11 nursing homes = 285
- 99% had advance care planning discussions
- 77% had DNR orders in place after palliative care consult
- 54% transitioned to the formal hospice program
- 46% residents reported pain at time of consult—86% improved with palliative care

*Financial Viability:* The Four Seasons program has been growing and expanding in Henderson County for over 25 years, and its dominant presence provides it with a “captive audience” for its services. This dynamic alone might make it difficult to replicate in other areas. The organization believes strongly in the patient benefit of integrating palliative care services with traditional hospice. However, the palliative care portion of the organization is struggling financially, and has not been able to meet its goal to become revenue neutral.<sup>39</sup> Administrators believe that a break-even budget can be achieved with the recruitment of the right staff.

*Lessons Learned from Four Seasons Hospice and Palliative Care:*

- It is important to hire hospice and palliative care providers who are familiar with and appreciate the nursing home culture.
- The palliative care consultant who contributes to an effective partnership recognizes that she/he is a guest in the nursing home setting.
- Some nursing home staff has trouble differentiating between palliative and hospice care. This is especially true when the same entity is providing both services. While there is overlap in the philosophy of care between palliative care and hospice, it is helpful to define the differences as they relate to patient eligibility, regulatory requirements and payer considerations.
- Some nursing home staff self-identify as providers of palliative care services. For this reason, the nursing home-palliative care partnership works best when palliative care program directors and consultants can clearly articulate how the skills and services they bring will complement and extend staff capabilities.
- Nursing homes are relationship-based. Consistent assignment of the same consultants to a given nursing home has significant advantages.
- Nursing home staff members are very receptive to end-of-life and palliative care education.
- A key element to building an effective nursing home partnership is establishing a relationship with the Medical Director. Resistance is not uncommon.
- Identifying reasonable, realistic goals for the palliative care consultation is good business. In the experience of Four Seasons Hospice and Palliative Care, it is better to under-promise and over-deliver positive outcomes.
- Program development is best cultivated if the start-up is limited in size and scope with expansion predicated on demonstrated success.

### 3. Nursing Home Services Integrated Palliative Care Model

An increasingly prevalent model for improving quality of care in nursing homes is to base a geriatric nurse practitioner in the home. This model has been shown to reduce unnecessary hospitalizations because nurse practitioners are able to provide a unique and intensive level of care to residents. Their training particularly lends itself to palliative care. Three different examples of the nurse practitioner method are given here—Morningside House and Hebrew Home (both were site visit locations for this project) and Evercare Palliative Care, a managed care option offered by UnitedHealth Group.

#### *Morningside House*

Morningside House<sup>v</sup>, founded in 1852 and located in the Bronx in New York City, is a nonprofit, non-sectarian 386-bed nursing home with care provided by an interdisciplinary team of professionals. Services include long-term nursing, Alzheimer’s and dementia care and a rehabilitative program. The home is affiliated with the Alzheimer’s Foundation’s Aging in America—Continuing Care program.

*Program Description:* Morningside House initiated its palliative care program through a grant received from the United Hospital Fund. Although not involved formally in any culture change movements (see culture change discussion below), Morningside leadership believes that they are bringing culture change to all levels of their organization by “operationalizing palliation.”<sup>40</sup> As stated by the Morningside CEO:

*“To do palliative care, you need culture change.”<sup>41</sup>*

The staff interdisciplinary team found at Morningside, which includes clinicians, social workers and chaplains, mirrors in many ways hospice interdisciplinary teams. Hospice philosophy is reflected in many Morningside policies, such as round-the-clock visiting hours:

*“Pizza at midnight is okay. Recliner next to mom’s bed is fine.*

*We provide resident-centered care.”*

*— Morningside Vice-President for Nutritional Services.*

*Results:* The domains of quality palliative care articulated by the National Consensus Project are all reflected in Morningside care. A year ago the organization established its own palliative care team. Advance care directives are discussed with residents on admission to the home. The social work staff uses the MOLST (Medical Orders for Life Sustaining Treatment, link available in Appendix C) system for uniformity.<sup>6</sup> In the project site visit inter-

<sup>v</sup> <http://www.allcarenet.org/memdir/MORNINGS.html>

<sup>vi</sup> MOLST (Medical Orders for Life-Sustaining Treatment) and POLST (Physician Orders for Life-Sustaining Treatment) forms require state authorization.

view, the social worker employed at Morningside emphasized the organization's focus on palliative care:

*"I'm here because I have a strong interest in palliative care—a passion for palliative care."*<sup>42</sup>

The organization uses a nurse practitioner model of care, and is trying to "grow" its own nurse practitioners by providing tuition reimbursements and encouraging two-year nurses to go back to school for four-year degrees (with an online program) and CNAs to go back for nursing degrees. Morningside offers flex schedules and mentoring. Pastoral services are offered both by staff and from the community, and bereavement is honored throughout the house—with memorial services and bedside memorials for staff.

*Financial Viability:* Facility budget numbers indicate that the Morningside interventions are cost effective in terms of retention and reduced turnover. The Morningside leadership believes its model is replicable, in the right organization with the right leadership, but a smaller home might have difficulty providing such a broad range of services. In addition, the volume of residents necessary to financial viability may make it difficult for the average 120-bed nursing home to develop this model.

#### *Lessons Learned from Morningside House:*

- When implementing a palliative care program, it is important to have strong leadership with a passionate commitment to palliative care:

*"It's all about leadership."*<sup>43</sup>

- Morningside House administrators discovered that for their program it is important to look at religious and cultural issues when hiring and training staff.
- Many nursing home residents and their families do not understand palliative care and may equate it with "giving up." For that reason it is important to develop trust and relationships with residents and families before educating them about palliative care.
- At Morningside, the CNAs are important providers of palliative care, so the nursing home trains its CNAs in palliative care.
- Tested tools, such as MOLST, can be helpful in guiding advance care planning and advance directive discussions.

#### ***The Evercare Model***

Evercare is a comprehensive Medicare HMO product that provides coverage for frail elderly, disabled and chronically ill individuals in nursing homes in the United States, and currently serves over 100,000 enrollees in 35 states through a variety of Medicaid, Medicare and private pay health plans. It was founded in 1987 by two Minnesota nurse practitioners who sought to reduce fragmentation in geriatric care by creating a model of care that emphasized collaborative relationships with their residents, caregivers and health care professionals. The company received Medicare demonstration status for its plans in 1995, and worked with state long-term care Medicaid systems to develop programs that integrate and coordinate medical, home and community-based services.

*Program Description:* With the ultimate goal of reducing the costs of emergency department visits and hospitalizations, Evercare integrates medical, health and social support services to enhance both quality of life and access to health care. Geriatric nurse practitioners develop and manage customized care programs for enrollees, and coordinate services. These services include a focus on advance care planning and communication with the family.

Evercare nurse practitioners come into nursing homes at least once a month to serve their residents, but they are not part of the nursing home staff. Often they work alongside staff practitioners, as they do at Morningside Home in New York. Physician services are also available, and nurses and social workers assist as needed with care management.

*Results:* Nursing homes benefit from Evercare contracts because the risk for costs of a resident's care then shifts to Evercare, which guarantees payment, regardless of related expense. However, the structure of the Evercare managed care plan, along with the fact that Evercare offers its own hospice and palliative care services, creates a disincentive for Evercare residents to elect hospice services from community-based providers. As a result, hospice referrals may drop dramatically—or disappear completely—when Evercare is in a facility. Although Evercare yields good quality measures for nursing homes, it does not offer the full range of end-of-life symptom management and spiritual and bereavement services offered by hospice.<sup>44</sup>

*Financial Viability:* Models such as Evercare, or models within any full-risk capitated environment, have a strong business case for nursing home palliative care services, because of the resulting reduction in risk of hospitalization.

### **Hebrew Home**

Hebrew Home of Greater Washington<sup>vii</sup> is a nonprofit nursing home that has been serving the Washington, D.C. community for 96 years. It offers independent living, assisted living and outpatient medical care, along with nursing home and rehabilitative services.

*Program Description:* Hebrew Home's model is different than previously described models in that home leadership has chosen not to have a separate or formal palliative care program on purpose. They believe the high caliber of nursing home care they provide is palliative care. Care is based on a "care and comfort" planning process that starts at admission to the home. Individualized care plans are developed with an interdisciplinary team involving the resident and family, physician, social worker, charge nurse, activity director, dietitian and nurse aides responsible for the resident's care. The home provides a strong pain and symptom management program, and the goals of care and symptom management change according to resident needs. Daily "stand-up" meetings provide ongoing assessment of care plans. A key feature of this facility in providing high quality palliative care and keeping resident's out of the hospital is having the medical staff on-site. The

<sup>vii</sup> [http://hhgw.convio.net/site/PageServer?pagename=ltc\\_services](http://hhgw.convio.net/site/PageServer?pagename=ltc_services)

Medical Director and nurse practitioners are salaried by the home.

Both the CEO and COO at Hebrew Home are Eden Associates (see discussion in Appendix D), and many Eden principles are in place at Hebrew Home. The home has gardens, pets and intergenerational day care. It is noteworthy that this home also offers 24 hour visiting hours for family and friends of residents.

*Results:* Success of the program relies on a strong volunteer base, and Hebrew Home staff believes their volunteer “doula” program could be easily replicated in other homes. In their training, Hebrew Home doulas learn about: death and dying; the physical, emotional and spiritual needs of individuals at the end of life; the process of dying from diagnosis to death; hospital and nursing home systems; advance directives; and HIPAA regulations. Doulas visit their patients at least once a week for up to two hours, and attend regular volunteer meetings for continuing education and support. They stay with their patients even during periods of hospitalization, providing important continuity of care. Hebrew Home doulas currently serve 30 residents.

Hebrew Home leadership feels that a key element for palliative care programs in nursing homes is family education. This is also an area where they feel they need improvement (for example, often, despite the best efforts of the team, a family insists that “everything” be done).

*Financial Viability:* The “closed model,” where a nursing home provides a salary to its physicians and nurse practitioners, is in contrast to other models where clinicians receive payment by billing Medicare Part B for services provided to individual residents. Nursing home literature relates that certain outcomes, such as hospitalization rates and response to emergencies, are better with the salaried model compared to the independent physician billing model.

*Lessons Learned from Hebrew Home:*

- Trained volunteers can make a significant difference and improvement in quality of life for residents and families, especially those who are confronting end-of-life issues.
- At the Hebrew Home, resident hospitalizations were reduced by having medical staff on-site and salaried by the nursing home.
- Family education about palliative care can be a key to success for a palliative care program.

#### **4. Hospice Care Model**

In this model, Medicare-certified hospice providers bring comprehensive interdisciplinary end-of-life/hospice care to nursing home residents and families who are eligible for and elect the hospice benefit.

*Program Description:* Hospice has been considered the gold standard for the delivery of palliative care services for the terminally ill and successful hospice/nursing home collabo-



rations are known to enhance quality measures for **all** residents of a nursing home. One researcher interviewed in the project survey found that:

*“...homes with strong hospice collaborations have few resident unmet needs and have greater satisfaction, less invasive treatments, fewer hospitalizations and provide better care practices.”<sup>45</sup>*

A hospice presence in a nursing home heightens staff awareness of pain and symptom management, and increases psychosocial and spiritual support for residents. Hospice bereavement support for both families and staff after a resident’s death is noted as a valuable contribution to nursing homes.

*Results:* The administrator for a nursing home in Sioux City, Iowa explains how her facility benefits from its hospice collaboration:

*“The presence of the hospice staff gives our staff needed expertise and support. We get frustrated when our best efforts do not improve the resident’s condition. There is a real sense of relief to have someone else helping out and providing a different perspective and supporting what we are doing. Hospice staff comes in at a tender time. Our staff has to keep up with the daily routine for all our residents; hospice staff can dedicate the time needed to be a good listener—and to provide support before, during and after the loss.”<sup>46</sup>*

The partner hospice of this nursing home conducts a formal in-service on hospice and end-of-life care for nursing home staff twice a year. In turn, the facility educates the hospice on nursing home regulatory considerations. Experts interviewed for the project survey noted that the most successful hospice collaboration models are ones where there is both a formal and informal exchange of knowledge.

Because of their reliance on relationships, communication and consistency, these collaborations do not work in environments with high turnover—a stable staff is essential. Hospice/nursing home collaborations work best when the two entities overcome the potential “culture” clash and view themselves as having equal value. It is also important to have policies and procedures that clarify the respective provider roles.

Hospice staff is sometimes perceived as arrogant when entering the nursing home environment, assuming that facility-based staff is inexperienced at caring for residents at the end of life. In some cases, this assessment of arrogance may be valid; in others, it may be representative of a defensive posture by nursing home staff. What is clearly true is that nursing home and hospice staff have a great deal to teach each other about the care of residential geriatric residents.

There are several advantages to be realized from nursing home-hospice partnerships. For example, the collaboration brings the strengths of two provider types to nursing home residents and their families. Secondly, each provider occupies a distinctive niche in the community, and each benefits from the credibility and visibility of the other. The joint

venture can serve as a marketing advantage for both partners.

*Financial Viability:* One of the challenges nursing homes and hospice partners confront is the choice residents must make about which entity will be the principal provider of his or her clinical care. Skilled Nursing Facilities (SNFs) providing Medicare reimbursed rehabilitative and restorative services after an acute hospital stay, and Certified Medicare Hospices are both Medicare Part A Providers. Because Medicare requirements stipulate that patients may receive services from only one Part A Provider at a time, SNF residents eligible for hospice care (those who are certified by a physician to have six months or less to live if the disease pursues its normal course) must choose between the two. The choice has clinical services and financial consequences for the resident, the nursing home and the hospice.

For residents eligible for the Medicare SNF services, coverage includes defined care management services for skilled nursing care or rehabilitation and for room and board fees. Medicare pays the nursing home directly. The patient cannot access his/her hospice benefit.

For residents eligible for the Medicare Hospice Benefit, coverage covers costs associated with interdisciplinary palliative care management of the symptoms presented by a life-limiting condition including psycho-social support for both the resident and his/her family. The resident foregoes curative therapies and interventions. Payment for Medicare services goes directly to the hospice provider—who may in turn purchase some services from the nursing home. Medicare does not cover room and board expenses for the hospice patient so this nursing home expense must be covered out-of-pocket by the patient or his/her representative or by supplemental insurance if such exists. The patient cannot access his/her SNF benefit. As a result, virtually no nursing home residents receiving Medicare SNF services receive hospice services.

For nursing home residents who are covered by Medicaid insurance or are private pay, the payment considerations are somewhat more complicated and vary by State. As noted elsewhere in this report, Medicaid is by far the largest payer for nursing home services. In general, the services covered by Medicaid are less comprehensive than those covered by the SNF benefit and the payment rate is lower. Payment goes directly to the nursing home.

For nursing home residents who are covered by Medicaid, hospice may be elected. The services covered by Medicaid mirror those covered by Medicare but the rates are lower. Some States underwrite both hospice services and room and board costs for nursing home Medicaid residents. The payment, frequently delayed, goes to directly the hospice which then pays the nursing home on the basis of a contractual agreement.

As described above, there is a financial incentive for the beneficiary and his or her family and for the nursing home to elect SNF benefit until eligibility expires thus delaying or in some cases (if the resident dies during his or her skilled benefit period) denying access to hospice care altogether.



## D. NURSING HOME QUALITY INITIATIVE

*Palliative care in nursing homes rests at the nexus of quality, workforce, and culture change efforts that are already in progress in the nursing home environment.*

The nursing home industry is one of the most heavily regulated industries in the United States. Evidence of substandard care, neglect and abuse prompted a tightening of federal nursing home standards in 1987 when the Federal Nursing Home Reform Act (OBRA 87) created a set of national minimum set of standards of care and rights for people living in certified nursing homes. It directs that nursing homes receiving Medicare or Medicaid funding must provide services so that each resident can “attain and maintain her highest practicable physical, mental and psycho-social well-being.” The law, which went into effect in October 1990, improved the quality of care in nursing homes significantly. It brought greater focus to patient assessments and care planning, diminished use of restraints and established standards to improve nurse aide care quality.<sup>47</sup> The Institute of Medicine reported in 2001 that the quality of nursing homes was improving, and citations for serious deficiencies were on the decline.

Despite these recent improvements, there is still concern in the field about the quality, cost and accessibility of care and the adequacy of oversight and enforcement mechanisms. Serious problems, including pain, pressure sores, malnutrition and urinary incontinence, continue to plague nursing homes.<sup>48</sup> To address these continuing concerns, the Centers for Medicare & Medicaid Services (CMS) introduced the Nursing Home Quality Initiative (NHQI)<sup>viii</sup>, a program designed to improve the quality of care in nursing homes throughout the country. With this multi-faceted project, launched in 2002, CMS worked with measurement experts, the National Quality Forum and a diverse group of nursing home industry stakeholders to adopt a set of improved nursing home quality measures. While these efforts have focused on clinical quality outcome measures, they include staff recruitment and retention, and culture change initiatives.

The improvement efforts of the NHQI can inform palliative care programs in nursing homes, and palliative care initiatives should build on the foundation they provide. Some of the components of the initiative are:

- **Survey & Certification:** CMS and state survey and certification agencies maintain and improve their existing regulatory enforcement efforts.
- **Quality Measures:** CMS promotes consumers’ access to information about the quality of care in specific nursing homes through publicly-reported quality measures available on CMS’s Web site for consumers (<http://www.medicare.gov>).
- **Culture Change & Workforce Efforts:** Nursing home stakeholders collaborate to promote and support efforts to improve nursing home quality of care.
- **Quality Improvement Organizations (QIOs)** offer community-based quality improvement assistance programs to nursing home providers seeking to improve their performance on the Quality Measures.

<sup>viii</sup> <http://www.cms.hhs.gov/NursingHomeQualityInits/>

## 1. Survey & Certification

The primary component for assuring quality of care in nursing homes is direct regulation through the survey and certification system. Nursing homes cannot operate unless they are licensed by the state in which they are located, and they cannot receive Medicare and Medicaid funding unless they are certified as meeting the federal quality standards. Federal standards, survey processes and enforcement mechanisms overwhelmingly dominate the quality assurance system. CMS relies on the states to actually administer the process, and CMS's regional offices oversee and monitor the state activities. Unfortunately, standards for determining the existence of a deficiency, identifying if actual harm has occurred and designating scope and severity levels vary from region to region, state to state and even within states. These inconsistencies result in a lack of predictability that compromises the integrity of the entire process.

Through the NCQI, CMS has announced a variety of efforts to strengthen the regulatory process, including targeting chronically poor-performing nursing homes, increasing training of surveyors, expanding the list of problems on which surveyors are to focus, improving the procedures for sampling residents whose care is to be reviewed, reducing the predictability of the timing of the survey and strengthening the federal oversight role. However, the present regulatory system can develop into an adversarial process between surveyors and nursing homes rather than enabling all parties to work together to improve quality of resident care and services. A more reciprocal approach to surveys needs to be developed—one that allows surveyors and caregiving staff to work together, not only on promoting and achieving sustained compliance, but on identifying and implementing best practices to meet individual care needs. The survey and enforcement system needs to focus on outcomes and continuous quality improvement, such as the culture change movement, rather than on process. A more effective approach is to shift the emphasis from punishment to guidance and problem solving.

## 2. Quality Measures

The nursing home quality measures come from a nursing home's MDS, or Minimum Data Set. Nursing homes certified by Medicare and Medicaid are required to perform a comprehensive assessment of each resident, using the MDS, upon admission and periodically after that. The MDS is collected and reported by all nursing homes on residents' physical and clinical conditions and abilities, as well as their preferences and care wishes.

The quality measures are under constant review and revision. In 2004 the initial set of measures was enhanced to reflect the recommendations of the National Quality Forum, a voluntary standard setting consensus-building organization representing providers, consumers, purchasers and researchers. In 2005 an additional measure was added that tracks weight loss. This is a good example of a measure that causes some nursing homes to avoid care of the dying, or to hospitalize dying persons to avoid regulatory scrutiny of the weight loss that accompanies the normal dying process. Currently a total of fifteen quality measures are used to reflect quality of care at the nation's nursing homes and are reported on Nursing Home Compare, <http://www.medicare.gov/NHCompare>.

Each individual home receives the same Quality Improvement (QI) reports that are generated and given to the state and used as the quality measures for consumers on Nursing Home Compare. Since the implementation of the 2002 Nursing Home Quality Initiative most of the homes—through either CMS, the Quality Improvement Organizations, innovative culture change programs or the nursing home associations—are beginning to use the QI reports for continuous quality assurance and improvement. Addition of more palliative care measures to the data set is an important means of improving palliative care in nursing homes. One possible performance measure is hospitalization for potentially avoidable causes, such as urinary tract infections, respiratory infections, sepsis, wound infections and conditions such as pneumonia—where monitoring and early response might avoid the need for hospitalizing a nursing home resident.

### 3. Culture Change

*“When we transform nursing homes into human communities, places for living and growing, we will ultimately change the very nature of aging in America.”*

— *Rose Marie Fagan*  
*Former Executive Director, Pioneer Network*

Culture change efforts and programs provide glimpses of how nursing home culture, operations and outcomes can change. They imply that some improvement in resident and staff satisfaction can be obtained without increasing costs. Five areas in an organization are transformed by culture change: decision making, leadership, staff roles, the physical environment and organizational design. Improvement in all of these areas is essential for providing quality palliative care. Many homes are divided into “neighborhoods” and smaller “households” with their own names and often with their own entrances.<sup>49</sup>

While they employ varying strategies to achieve change, the different culture change initiatives work toward several common goals:

- Enabling residents to direct their care and activities;
- Creating living environments that are more like homes than institutions;
- Fostering close relationships between residents, family members, staff and communities;
- Empowering staff to respond to residents’ needs and desires;
- Promoting collaborative decision making; and
- Practicing continuous quality improvement.<sup>50</sup>

Recent research indicates that participating in the culture change movement can be cost efficient and positively affect a nursing home’s bottom line financially. Significant findings include:

- Homes participating with the Pioneer Network (see Appendix D for detail) generated an average additional \$2,093 per bed net income over comparable homes from 1996 to 2003.
- Homes participating with the Pioneer Network also improved operating margins by an average 9.5 percentage points over comparable homes from 1996 to 2003.<sup>51</sup>

It remains unclear whether or not the culture change ideas can be replicated across diverse nursing homes, or whether or not variants of these approaches can achieve social environment changes and improved outcomes across a range of care quality measures. Persistent tension remains between culture change efforts and their resident-centeredness and “over-medicalization”<sup>52</sup> of nursing homes that is perceived to depersonalize residents by classifying them as “patients.” However, several organizations embracing culture change systems are reporting improved clinical outcomes and a dramatic reduction in staff turnover,<sup>53</sup> prerequisites to the delivery of quality palliative care. More detail about culture change movements in nursing homes can be found in Appendix D.

#### 4. Workforce Efforts

Studies done by CMS and others repeatedly conclude that nurse staffing levels are intrinsic to high quality nursing home care. Our interviews reveal that nurse and frontline staffing levels are also related to the delivery of high quality palliative care. Nursing homes have ongoing challenges to quality improvement associated with the workforce. The difficult nature of nursing home work, combined with relatively meager pay and benefits for direct care workers, have been associated with periodic labor shortages and difficulties in worker retention, supervision and continuous training. A major challenge at both the national and state levels concerns the effective recruitment, training and retention of certified nursing aides. High staff turnover in nursing homes clearly has important consequences for the care of residents.

Through culture change quality initiatives, greater control is given to frontline workers (nurse aides who handle much of the day-to-day care of nursing home residents), as well as residents and their families. Usually staff is permanently assigned to a particular group of residents. Such consistent assignments allow frontline staff to learn more about residents, and enhance quality of care and job satisfaction. All of these interventions are known to increase the quality of palliative care programs as well.

Perspectives on organizational behavior and leadership also affect how nursing home leaders facilitate cultures of quality. The traditional structure of nursing homes has been a bureaucratic hierarchy with managers at the top dictating how the organization will comply with regulations. A recent study, *Nursing Homes as Complex Adaptive Systems: Relationship Between Management Practice and Resident Outcomes* (Anderson, Issel and McDaniel, 2003), suggests that nursing homes be viewed as “complex adaptive systems” in which there is social interaction and the ability to self-organize. The study findings are important because leadership and management practices from this perspective differ from traditional nursing home management. Study results indicate that

communication openness, participation in decision making, relationship-oriented leadership and less reliance on centralized control and rules have a positive influence on resident outcomes. These leadership practices are more likely to facilitate cultures of quality. This assumption is supported by findings in the Institute of Medicine report released in 2001, *Crossing the Quality Chasm: A New Health System for the 21st Century*, which recommends that developing effective teams, better coordination of care across organizational boundaries and redesigning care processes would improve care quality. Relationship-oriented leadership enables and facilitates these organizational development processes, which in turn are more likely to result in a culture of quality.

## 5. Quality Improvement Organizations (QIOs)

As part of NHQI, CMS made Quality Improvement Organizations (QIOs) responsible for providing technical assistance to nursing homes to help them improve their performance and to promote resident-centered care. The QIO Program consists of a network of 53 QIOs who are responsible for each state, territory and the District of Columbia. Nursing homes working with QIOs set clinical goals, perform staff and resident surveys and track CNA turnover rates. The overarching goal is to make sure residents get the right care at the right time, particularly residents from underserved populations. The program also ensures that federal payment is made only for medically necessary services, and investigates complaints about quality of care.<sup>54</sup>

CMS supports quality improvement organizations that also incorporate culture change features. An example is the Quality Partners of Rhode Island.<sup>ix</sup> In addition to working with nursing homes to improve their outcome measures and staff retention, Quality Partners works to help nursing homes move from institutional organizations towards a home-like, patient-centered environment using individualized care. To do this, Quality Partners uses a transformational change model and sponsors a culture change coalition.

For this discussion it should be noted that these quality initiatives are important vehicles for introducing the principles of palliative care in the nursing home environment. Palliative care principles are closely aligned with the NHQI, including the core factors of quality measures, cultural change, workforce efforts and continuous quality improvement (CQI) principles. Several domains of palliative care—for example, advance care planning and pain and symptom management—are already embraced in culture change initiatives.

## E. WHERE DO WE GO FROM HERE?

Interviews and site visits for this project reveal several areas where nursing homes suffer deficiencies and encounter obstacles to quality of care and quality of life—deficiencies and obstacles the homes themselves acknowledge and are seeking to improve. Staff recruitment, retention and training need to be improved. Transfers of care between sites of care need improvement. We need to eliminate unnecessary suffering in nursing homes, while meeting regulatory requirements. Regulatory barriers and financial disincentives to

<sup>ix</sup> <http://www.riqualitypartners.org/>

quality care must be addressed. We need communication across the continuum of care and inspired nursing home leadership.

Layered over these broad issues and touching on all of them is the need to make palliative care a standard in all nursing homes in the United States. Finding ways to help nursing homes incorporate palliative care principles and practices, including the critical elements of advance care planning and pain and symptom management, can contribute to the improvement of care for all residents—not just those who are at the end of life.

Opportunities for improving palliative care in nursing homes exist for all stakeholders in the system—for palliative care teams and consultants, hospices, nursing home leadership and staff, hospitals and residents and families. Available palliative care resources specific to nursing homes need an investment in marketing and distribution. In addition, gaps in tools should be identified, and a work list developed, with accountability delegated to appropriate organizations. Detailed suggestions for these opportunities are given in the following section, Looking to the Future.



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# 4

## LOOKING TO THE FUTURE

<b>A. Opportunities for Nursing Home Leadership and Staff</b> .....	4.1
<b>B. Opportunities for Palliative Care Teams and Consultants</b> .....	4.2
<b>C. Opportunities for Hospices</b> .....	4.3
<b>D. Opportunities for Hospitals</b> .....	4.3
<b>E. Opportunities for Patients and Families</b> .....	4.3
<b>F. Opportunities for Educational Institutions</b> .....	4.3

Nursing homes are working hard to deliver the quality and scope of services required by frail and vulnerable residents and expected by their families. However, limited financial resources, a changing resident population and staff turnover constitute significant ongoing challenges.

The trend for hospitals to discharge patients “quicker and sicker” is resulting in increased acuity in many nursing home settings. The phenomenon, which is expected to continue, carries with it a demand for more specialized on-site clinical expertise. The anticipated influx of elderly baby boomers who will predictably present with multiple chronic complex illnesses will stretch the resources of residential facilities still further. Complicating this scenario is an unbending and wholly inadequate reimbursement structure and a demanding federal and state regulatory environment within which nursing homes must operate.

The needs assessment for this project identified opportunities and strategies that nursing homes may wish to employ to better address the needs of their residents. These suggestions are organized below by target audiences.

## **A. Opportunities for Nursing Home Leadership and Staff**

- Due to the increase in acuity of nursing home residents, introducing palliative care consultant services brings access to expert pain management and symptom control for residents at no additional cost to the facility.
- Because the principles of palliative care are closely aligned with the core factors of culture change initiatives (quality long-term care), and several domains of palliative care (advance care planning and pain and symptom management), they offer opportunities for nursing home leadership to expedite and extend the integration of palliative care services within their homes. (See Appendix D, Nursing Home Change Efforts, for discussion of culture change initiatives).
- The challenge of staff retention can be addressed at least in part by offering consistent staffing opportunities, career ladders and training programs teaching palliative care concepts. A palliative care focus could be incorporated in training programs for LPNs who wish to become RNs.
- Palliative care “certifications” that move with staff could increase pride, expertise and possibly pay, and minimize the knowledge drain and costs resulting from high staff turnover.
- Well-trained volunteers can enhance a palliative care program. The “doula” program used at the Hebrew Home (see Nursing Home Services Integrated Palliative Care model discussion in Findings) is an example of a successful volunteer program.
- Internship rotations in nursing homes for disciplines such as social work and physical and occupational therapy provide good exposure for students to nursing home careers. Many students who train in nursing homes will return to them to take staff positions.
- Creating educational materials for residents and families that explain DNR orders and advance care planning can dispel misconceptions about the intent of these directives

and what they mean to the resident and the family.

- Involving frontline staff in resident palliative care planning can enhance nursing home residents' and their caregivers' quality of life.

## **B. Opportunities for Palliative Care Teams and Consultants**

- Once a palliative care team is providing services in a nursing home, it is important to give time and attention to educating residents and families about the special services they are receiving.
- Nursing home Medical Directors and attending physicians need access to information to help them understand billing considerations for palliative care services: a primary physician and a palliative care physician or nurse practitioner can legitimately bill and be paid for the same resident on the same day.
- In states where they are authorized, the POLST (Physician Orders for Life-Sustaining Treatment) and MOLST (Medical Orders for Life-Sustaining Treatment) paradigms and forms (see Appendix C for information), can provide guidelines for advance care planning discussions, and can assure continuity of goals of care and care plans as patients move from setting to setting.
- State and national nursing home association educational conferences provide opportunities for introducing palliative care content to the nursing home field. Other educational targets include: hospital discharge planners; social workers in nursing homes; physicians caring for nursing home-eligible residents; and educational interventions offered to staff in nursing home chains.
- The development of business and training tools are needed to spread palliative care in nursing homes. Following are examples of items that could be useful:
  - ◆ A “palliative care in nursing homes toolkit” for nursing home education;
  - ◆ Curriculum for nursing home Directors of Nursing that is either self-study or offered through a nursing association (See Geriatric ELNEC, Appendix C);
  - ◆ A “fast facts” educational series for CNAs and LPNs, similar to the EPERC series aimed at physicians (see Appendix C for link);
  - ◆ Curriculum on nursing home palliative care for nursing home Medical Directors similar to the ELNEC program (see Appendix C);
  - ◆ Educational interventions for MDS coordinators to maximize recognition of the concordance of palliative care with regulatory requirements;
  - ◆ Administrative “fast facts” series on Medicare billing and HIPAA regulations for palliative care; and
  - ◆ Assessment tools for nursing home Boards of Directors to assess quality of palliative care in their facilities.

### **C. Opportunities for Hospices**

- A formal collaboration with one or several nursing homes not only gives hospices opportunities to provide palliative care services to a population in need, but it can also increase a hospice census and length of stay (a financial benefit to the hospice).
- One way to encourage mutually beneficial partnerships between nursing homes and hospices is to offer reciprocal training sessions—hospice and palliative care providers offering education about their respective areas of expertise, and nursing home staff offering education to palliative and hospice providers about nursing home requirements and about the care of facility-based geriatric residents.

### **D. Opportunities for Hospitals**

- Integrating family and caregivers at all points of a resident's care, but especially at times of transition from one health care setting to another, can help provide consistent information and continuity in the provision of palliative care across settings.
- Direct communication between hospital providers and nursing home staff when sharing a resident's care will increase positive outcomes for the residents with palliative care needs who require expert transition management.

### **E. Opportunities for Residents and Families**

- Family members can request palliative care services or consultations for their loved ones living in nursing homes.
- State ombudsmen can assist residents and families seeking palliative care services. A national resource center to locate these can be found at [http://www.ltcombudsman.org/static\\_pages/help.cfm](http://www.ltcombudsman.org/static_pages/help.cfm).
- Family members and caregivers can be encouraged and supported in providing information (for example, on medications and procedures) to contribute to continuity when residents are transferred between nursing homes, hospitals and other health care facilities.

### **F. Opportunities for Educational Institutions**

Because nursing expertise is critical in the nursing home setting, integrating palliative care content into nursing school curricula will be an important step. The End-of-Life Nursing Education Consortium (ELNEC) is a current effort to improve end-of-life care in the nation through education. Information about ELNEC's courses for nurses can be found at <http://www.aacn.nche.edu/elnec/about.htm>

# 5

## REPORT SUMMARY

<b>A. The Case for Palliative Care in Nursing Homes</b> .....	5.1
<b>B. The Challenges</b> .....	5.1
<b>C. Models that Work</b> .....	5.2
<b>D. The Future</b> .....	5.3

## A. THE CASE FOR PALLIATIVE CARE IN NURSING HOMES

The demographics of nursing homes today are changing with the aging of our country. Interviews conducted for this project revealed that nursing homes are seeing more residents with chronic complex illnesses and multiple medical problems requiring sophisticated clinical interventions. Nursing homes report that their residents are staying longer—some for several years—and the number of people dying in nursing homes is also increasing dramatically. These trends will continue over the next decade and point to the fact that nursing homes have a high concentration of residents who would benefit from palliative care.

## B. THE CHALLENGES

While nursing homes strive to deliver quality care and a wide scope of services to their residents, limited financial resources, the changing resident population and high staff turnover constitute significant ongoing challenges. To many nursing home administrators and staff, providing palliative care services represents one more challenge to overcome. However, on the basis of the work conducted with support from this planning grant, it is clear that the field of palliative care can contribute to the solutions of some of the problems encountered by nursing home residents and staff. Those solutions can be framed in the context of the following findings distilled from this project's research:

- Advance care planning and pain and symptom management are targets consistently identified by nursing homes as goals for improvement. A concerted effort is needed to identify and test strategies that meet these goals.
- Transitions between hospitals and nursing homes are high risk events for residents, and project interviews revealed that transitions between sites of care are poorly managed. Communication, documentation, reconciliation of pharmaceutical regimens and care plans are often inadequate or in conflict. This problem has increased in recent years due to the simultaneous increase in patient complexity and changes in physician coverage. The decline of the role of the primary care physician as a source of continuity between inpatient and outpatient care, combined with the increasing time pressures experienced by hospitalists and discharge planners have combined to increase the risk of poor handoffs. HIPAA regulations further complicate the communication issue. Palliative care teams are well positioned to rebuild continuity bridges and follow residents as they move between hospitals and nursing homes—if adequate resources are allocated to staff these roles.
- Several programs interviewed for this study rely on partnerships to sustain palliative care programs in their nursing homes. Successful partnerships between hospices and/or palliative care teams and nursing homes require size, patience and flexibility. Although some services will eventually be financially self-sustaining, partners need to be able to contribute time to building the relationship, training and skill building without a revenue source.
- Larger nursing homes, or those affiliated with other services, find it more feasible to hire their own medical providers, contract for sufficient provider on-site care or attract fee-for-service palliative care consult services. Smaller homes will need to team up



with other nursing homes, hospices or hospital-based palliative care teams to create viable financial models for palliative care services.

- Training nursing home staff has limited impact in homes with high turnover. Regular on-site access for frontline nursing assistant staff to informal teaching and shared care planning with palliative care providers will be an effective way to improve palliative care in nursing homes. At the same time, building an awareness of palliative care needs with traditional nursing home leaders—Boards of Directors, administrators, Medical Directors and Directors of Nursing—will improve the recognition of palliative care needs.
- Training can also offset misinformation and misperceptions about regulatory barriers and measures. Inaccurate information about the MDS reporting system and regulatory agencies often drive conservative actions in nursing homes which may in turn be counter to a patient's wishes or best interests.

### C. MODELS THAT WORK

The barriers and challenges to providing palliative care for all nursing home residents are numerous, but not insurmountable. Survey interviews and site visits conducted for this project revealed many opportunities for improving palliative care for nursing home residents. The Looking to the Future section of this report lists opportunities for nursing home leadership and staff, palliative care teams and consultants, hospices, hospitals, residents and families and educational institutions. There is an emerging opportunity to build formal relationships between hospices and/or palliative care teams and nursing homes. Two key elements for maintaining these partnerships—leadership and communication—emerged in project interviews.

This research yielded four effective models for integrating preferred practices for palliative and hospice care in nursing homes:

- ***Palliative Care Consultation Service***  
Palliative care providers who are not employed by the nursing home provide and bill for consultative services to residents as requested by the nursing home Medical Director, the patient's attending physician or the nursing home Director of Nursing.
- ***Hospice-based Palliative Care Consult Service***  
Professional staff employed by a local hospice provides non-hospice palliative care consultative services as requested by the nursing home Medical Director, the patient's attending physician or the nursing home Director of Nursing.
- ***Nursing Home Services Integrated Palliative Care***  
Many nursing homes have embraced quality initiatives to improve resident and facility outcomes. While these efforts may not be defined as palliative care initiatives per se, they often incorporate some of the domains of care referenced in the National Quality Forum's Preferred Practices for Palliative Care and Hospice Quality, such as pain and symptom management. In this model, staff who provide these services may be employed directly by the nursing home. Alternatively, the care of individual residents in the nursing home may be managed under the direction of Evercare, a managed care insurance program which employs nurse practitioners to provide on-site services.

## ■ **Hospice Care**

Hospice-eligible nursing home residents receive specialized end-of-life palliative care services from contracted hospice providers.

These models, described in detail in the Findings section of this report, along with quality improvement efforts already being implemented in nursing homes, provide a framework for developing palliative care services in nursing homes. Our research findings also indicate that medical practitioners working in nursing homes would benefit from training and exposure to the principles of resident-centered care articulated in the culture change movement (see detail in Appendix D). Because palliative care approaches and philosophy are closely aligned with the culture change movement, culture change training will improve consistency and continuity of care for palliative care nursing homes residents.

## **D. THE FUTURE**

While the challenges facing nursing homes are distinct and unique, it appears that enhancing the nursing home palliative care repertoire can contribute to the quality of resident care, to patient, family and staff satisfaction and to the outcomes nursing home administrators seek to achieve. The findings of this project indicate that the nursing home field is receptive to tools and educational interventions that define and support the integration of best practices.

Some resources to support this effort have already been developed (see Appendix C, Palliative Care Resources and Tools). The efforts of the National Consensus Project and the preferred practices articulated by the National Quality Forum form a foundation for a palliative care initiative. To implement these domains of care and preferred practices, the nursing home field will require technical assistance and relevant clinical education specific to the nursing home environment—for both nursing home leadership and frontline staff. In addition, strategies for resolving policy, regulatory and financial barriers should be fully articulated and implemented. Future model development should use evidence-based outcomes and describe recommended funding options and define how they influence nursing homes' business plans.

The baby boom generation is turning 60, our life expectancies are increasing and we know that an increase in our population residing in nursing homes and other long-term care facilities is imminent. How to afford these services and still provide quality of care is a time-sensitive health policy issue facing our nation. The findings of this project and the models described in this report represent a beginning. We have an opportunity and an obligation to ensure that quality of life and quality of dying are reliable components of nursing home care in the future. Palliative care is one of the key solutions to this challenge.

# 6

## APPENDICES

**Appendix A: National Quality Forum Preferred Practices**

**Appendix B: Selected References**

**Appendix C: Palliative Care in Nursing Homes Resources and Tools**

**Appendix D: Nursing Home Change Efforts**

**Appendix E: Glossary**

## APPENDIX A

### National Quality Forum Preferred Practices<sup>1</sup>

1. Provide palliative and hospice care by an interdisciplinary team of skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors and others who collaborate with primary health care professional(s).
2. Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, seven days a week.
3. Provide continuing education to all health care professionals on the domains of palliative care and hospice care.
4. Provide adequate training and clinical support to assure that professional staff is confident in their ability to provide palliative care for patients.
5. Hospice care and specialized palliative care professionals should be appropriately trained, credentialed and/or certified in their area of expertise.
6. Formulate, utilize and regularly review a timely care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals and needs of the patient and family, and to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care.
7. Ensure that upon transfer between health care settings, there is timely and thorough communication of the patient's goals, preferences, values and clinical information so that continuity of care and seamless follow-up are assured.
8. Health care professionals should present hospice as an option to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.
9. Patients and caregivers should be asked by palliative and hospice care programs to assess physicians'/health care professionals' ability to discuss hospice as an option.
10. Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis and the benefits and burdens of potential interventions.
11. Provide education and support to families and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.
12. Measure and document pain, dyspnea, constipation and other symptoms using available standardized scales.

<sup>1</sup> National Quality Forum (NQF), National Priorities for Healthcare Quality Measurement and Reporting: A Consensus Report, Washington, DC: NQF; 2004.

13. Assess and manage symptoms and side effects in a timely, safe and effective manner to a level that is acceptable to the patient and family.
14. Measure and document anxiety, depression, delirium, behavioral disturbances and other common psychological symptoms in a timely, safe and effective manner to a level that is acceptable to the patient and family.
15. Manage anxiety, depression, delirium, behavioral disturbances and other common psychological symptoms in a timely, safe and effective manner to a level that is acceptable to the patient and family.
16. Assess and manage the psychological reactions of patients and families (including stress, anticipatory grief and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss.
17. Develop and offer a grief and bereavement care plan to provide services to patients and families prior to and for at least 13 months after the death of the patient.
18. Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis and advance care planning, and to offer support.
19. Develop and implement a comprehensive social care plan that addresses the social, practical and legal needs of the patient and caregivers, including but not limited to relationships, communication, existing social and cultural networks, decision making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.
20. Develop and document a plan based on an assessment of religious, spiritual and existential concerns using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.
21. Provide information about the availability of spiritual care services, and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships.
22. Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.
23. Specialized palliative and hospice spiritual care professionals should build partnerships with community clergy and provide education and counseling related to end-of-life care.
24. Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including but not limited to focus of decision making, preferences regarding disclosure of information, truth telling and decision making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering and grieving, and funeral/burial rituals.
25. Provide professional interpreter services and culturally sensitive materials in the patient's and family's preferred language.

26. Recognize and document the transition to the active dying phase, and communicate to the patient, family and staff the expectation of imminent death.
27. Educate the family on a timely basis regarding the signs and symptoms of imminent death in an age-appropriate, developmentally appropriate, and culturally appropriate manner.
28. As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for the site of death, and fulfill patient and family preferences when possible.
29. Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase, and address concerns and fears about using narcotics and analgesics hastening death.
30. Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.
31. Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient's death, when the family remains the focus of care.
32. Document the designated surrogate/decision-maker in accordance with state law for every patient in primary, acute and long-term care and in palliative and hospice care.
33. Document the patient/surrogate preferences for goals of care, treatment options and setting of care at first assessment and at frequent intervals as conditions change.
34. Convert the patient treatment goals into medical orders, and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services and hospital care, through a program such as the Physician Orders for Life-Sustaining Treatment (POLST) program.
35. Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to HIPAA regulations, for example, by using Internet-based registries or electronic personal healthy records.
36. Develop health care and community collaborations to promote advance care planning and the completion of advance directives for all individuals, for example, the Respecting Choices and Community Conversations on Compassionate Care Programs.
37. Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end of life.
38. For minors with decision-making capacity, document the child's views and preferences for medical care, including assent for treatment, and give them appropriate weight in decision making. Make appropriate professional staff members available to both the child and the adult decision-maker for consultation and intervention when the child's wishes differ from those of the adult decision-maker.

## Appendix B

### Selected References Nursing Homes and Palliative Care

- 1. Robert Applebaum and Michael Payne, “Managing long-term care, herding cats, and other 21st century mysteries,” *Gerontologist* 46, no.5 (2006):698. (3 pages)**  
Ironically, this rigorously means-tested Medicaid program results in older people, most of whom had never received welfare assistance, living their final years as wards of the state, while at the same time creating a financial hardship for most states and bringing criticisms from providers about inadequate funding. An irrational plan for financing, inadequate support for workers, bad regulations, funding and quality monitoring systems that focus on providers rather than consumers, and uncoordinated service systems are not individual organizational problems and thus require systemic solutions.
- 2. John E Baer, “The cost of inadequate leadership,” *Nursing Homes* 55, no.9 (2006):60. (2 pages)**  
Effective management and supervision are key to achieving a competent and committed workforce. Nursing home administration must provide training to assist managers and supervisors in developing the skills needed to be effective and efficient leaders. Most nursing home supervisors and managers are selected based on their performance in non-supervisory positions in their respective disciplines. It is essential that nursing home administrators provide their supervisors and managers with the management and leadership skills needed to establish a healthy workplace that contributes to the mental health, high morale, and productivity of its employees. The lack of supervisory, management, and leadership skills are a major contributor to high nursing home employee turnover. A smart business decision is to invest in the development of your supervisors and managers. Expose them to leadership training.
- 3. Jane E Bostick, Marilyn J Rantz, Marcia K Flesner, and C Jo Riggs, “Systematic review of studies of staffing and quality in nursing homes,” *Journal of the American Medical Directors Association* 7, no.6 (2006):366-376. (11 pages)**  
Evaluated a range of staffing measures and data sources for long-term use in public reporting of staffing as a quality measure in nursing homes. Eighty-seven research articles and government documents published during 1975-2003 were reviewed and summarized. Relevant content was extracted and organized around 3 themes: staffing measures, quality measures, and risk adjustment variables. Data sources for staffing information were also identified. Staffing measures ranged from staff ratios (number of nursing or direct care staff per resident or bed) to staff turnover rates. Quality measures were a proxy measurement for quality care and were classified as either resident outcomes (such as pressure ulcers or catheter use) or facility outcomes (such as hospital admissions, mortality rates, or code violations). Risk adjustment/control measures indicated variables that were used in the studies to factor out any extraneous effects that might impact results. The findings suggest an association between higher total staffing levels (especially licensed staff) and improved quality of care. Studies also indicated a relationship between high turnover and poor resident outcomes. Functional ability, pressure ulcers, and weight loss were the most sensitive quality indicators linked to staffing. The best national data sources for staffing and quality included the Minimum Data Set and Online Survey and Certification Automated Records (OSCAR). However, the accuracy of this self-reported information requires further reliability and validity testing. It is concluded that a nationwide instrument needs to be developed to accurately measure staff turnover in nursing homes.



4. **HE Brandt, L Deliens, JT van der Steen, ME Ooms et al, “The last days of life of nursing home patients with and without dementia assessed with the palliative care outcome scale,” *Palliative Medicine* 19, no.4 (2005):334.**

The aim of this study was to assess the Palliative care Outcome Scale (POS) for terminally ill nursing home (NH) patients in the Netherlands.

Methods: A prospective observational study of patients with a life-expectancy of six weeks or less in 16 Dutch NHs. NH staff rated the patient characteristics and measured palliative care with the POS, including items on physical, psychosocial, informational, spiritual and practical aspects.

Results: POS nonscores (not applicable; unknown) were mainly found in the psychosocial and spiritual domains, particularly in patients with dementia. Mean scores for non-demented patients and patients with dementia were favorable for the majority of the POS items.

Conclusion: According to the NH staff, fairly good quality care was provided, but the psychosocial and spiritual aspects of care need to be addressed more in the last days of the dying NH patient's life. The results indicate that the POS is an appropriate instrument to assess not only cancer patients, but also non-cancer and (moderately) severely demented patients.

5. **Kevin Brazil, Paul Krueger, Michel Bedard, Mary Lou Kelley, et al, “Quality of care for residents dying in Ontario long-term care facilities: Findings from a survey of directors of care,” *Journal of Palliative Care* 22, no.1 (2006):18. (10 pages)**

The purpose of this study was to collect information on the practice of end-of-life (EOL) care in long-term care (LTC) facilities in the Province of Ontario, Canada. A cross-sectional survey of directors of care in all licensed LTC facilities in the province was conducted between September 2003 and April 2004. Directors of care from 426 (76% response rate) facilities completed the postal survey questionnaire. The survey results identified communication problems between service providers and families, inadequate staffing levels to provide quality care to dying residents, and the need for training to improve staff skills in providing EOL care. Directors of care endorsed the use of a number of strategies that would improve the care of dying residents. Logistic regression analysis identified the eight most important items predictive of facility staff having the ability to provide quality EOL care. The findings contribute to the current discussion on policies for meeting the care needs of residents in LTC facilities until life's end.

6. **John R Brechtel, Shaiqua Murshed, Peter Homel and Marilyn Bookbinder, “Monitoring symptoms in patients with advanced illness in long-term care: A pilot study,” *Journal of Pain and Symptom Management* 32, no.2 (2006):168-174.**

The Edmonton Symptom Assessment Scale (ESAS) was administered daily by nursing staff in a long-term care facility (LTCF) to monitor symptoms. Scores greater than or equal to 5 on a 0–10 scale were considered moderate-to-severe and triggered prompt treatment. One hundred and eight patients with advanced illness and perceived prognosis of less than six months were identified for rapid symptom management over a seven-month period. Forty-six (43%) of these patients had at least one episode of moderate-to-severe symptoms during the follow-up period. Thirty-one of these patients (67%) had a primary diagnosis of advanced AIDS and 12 (26%) had advanced cancer. Pain was the most frequent of the 15 symptoms measured, occurring in 29 patients. In the case of pain ( $p=0.001$ ), tiredness ( $p=0.004$ ), and well-being ( $P=0.003$ ), rapid symptom management led to significantly improved distress scores within 48 hours. These data suggest that it is feasible for nurses in an LTCF to use the ESAS on a daily basis to assess patients and obtain prompt treatment for distressful symptoms. Rapid treatment of symptoms can be an important quality indicator in nursing home patients with advanced illness.

7. **M Bourbonniere, Z Feng, O Intrator, J Angelelli, V Mor, and JS Zinn, “The use of contract licensed nursing staff in U.S. nursing homes,” *Medical Care Research Review* 63, no.1 (2006):88.**

The extent to which nursing homes rely on the use of contracted licensed staff, factors associated with this staffing practice, and the resultant effect on the quality of resident care has received little public attention. Merging the Online Survey Certification and Reporting System database with the Area Resource File from 1992 through 2002, the authors regressed organizational and market-level variables on the use of 5% or more contract full-time equivalent registered nurses and licensed practical nurses. Since 1997, the proportion of facilities using 5% or more contract licensed staff more than tripled. Use of contract nurses was associated with more deficiency citations, characteristics of poorer facilities, and tight labor markets. Nursing homes increasingly rely on contract nurses. The failure of nursing homes to attract and retain a competent, stable workforce creates a vicious cycle of staffing practices, which may lead to decline in quality of care.

8. **Gwendolen T Buhr and Heidi K White, “Quality improvement initiative for chronic pain assessment and management in the nursing home: a pilot study,” *Journal of the American Medical Directors Association* 7, no.4 (2006):246-253. (8 pages)**

Investigated options for improving the assessment and management of chronic pain in a nursing home setting through a method of continuous quality improvement in a North Carolina nursing home. A quality improvement team reviewed current clinical practice guidelines, updated the policies and procedures, developed tools for pain assessment, and educated the staff in pain assessment and management principles. A series of educational programs were held at the nursing home and three related facilities. To assess patient and family satisfaction with pain management, 15-20 patients and family members were interviewed. The staff's pain-related knowledge was measured with multiple-choice tests before and after the educational program. Before the intervention, the mean number of questions correct on the staff test was highest among the registered nurses (RNs), intermediate among the licensed practical nurses (LPNs), and lowest among the certified nursing assistants (CNAs)—13.7, 12.4, and 9.4 out of 16, respectively. After the intervention the scores were 16 for the RNs, 12.9 for the LPNs, and 12.0 for the CNAs. Results suggest that the pain assessment intervention showed improvement in documentation and that the level of satisfaction for both the patients and families also increased.

9. **MW Carter and FW Porell, “Nursing home performance on select publicly reported quality indicators and resident risk of hospitalization: Grappling with policy implications.” (Morgantown, WV: Center on Aging and Department of Community Medicine, School of Medicine, West Virginia University). [mcarter@hsc.wvu.edu](mailto:mcarter@hsc.wvu.edu)**

This study examines how resident risk of hospitalization varies in relation to facility performance on select quality indicators (QIs). Using a 15% sample, three years of Medicaid reimbursement data from over 525 nursing homes (NHs) were linked with four years of hospital claims data and facility-level data to investigate whether residents of NHs with worse (better) than expected performance on QIs experienced increased (decreased) risk of hospitalization. Logistic regression results indicate that variations in hospitalization risk among NH residents are explained in part by facility performance on QIs. Residents from NHs with more decubitus ulcers, with greater use of physical restraints, and with a higher than expected incidence of unexplained weight loss/gain experienced increased risk of hospitalization.

10. **NG Castle and BB Longest, “Administrative deficiency citations and quality of care in nursing homes,” *Health Services Management Research* 19, no.3 (2006):144.**

In this investigation, we examine deficiency citations for administration in nursing homes. Administration is defined as the top managers in each facility, consisting of the nursing home

administrator and director of nursing. We examine the association between deficiency citations for administration (indicating poor administration practices) and quality of care. Regulators, as well as consumers, are interested in this association. Data used came from the 1996-2004 Online Survey, Certification and Recording (OSCAR) data, representing approximately 17,000 facilities per year. We find that 5% of facilities received a deficiency citation for administration, and lower facility quality is associated with these administration deficiency citations.

**11. Anonymous, "Creating 'choice' environments," *Nursing Homes* 55, no.9 (2006):36. (4 pages)**

One of the most difficult decisions family members must make is deciding that their mother or father needs more assistance than they can provide. At Chicago-based Lancaster Health Group, which operates seven nursing home facilities, they started the Choosing How Our Individualized Care Evolves program (C.H.O.I.C.E.) in January 2003 to allay these concerns. They wanted to create an environment that made that adjustment quicker. They wanted their homes to be a pleasant surprise for the resident and an enjoyable place for the family to visit. Their in-house activities were upgraded to include more educational programs such as documentary films, horticulture classes, and learning about the facility pets. To make it easier for residents to communicate with families, many of their facilities are now providing cell phones to alert residents. While the cost per day of operating the program is significant, the increase in their Medicare census has made this program cost-effective; they have experienced a significant increase in their Medicare census since starting the C.H.O.I.C.E. program

**12. Eileen R Chichin. "Teaching palliative care in the nursing home," *Journal of the American Geriatrics Society* 52, no.1 (2004):157.**

*Improving Nursing Home Care of the Dying: A training manual for nursing home staff*, edited by M. L. Henderson, L. C. Hanson, and K. S. Reynolds, is reviewed.

**13. Sally Cobb. "A lovely bouquet goes a long way," *Nursing Homes* 54, no.10 (2005):55. (2 pages)**

Digging through Piedmont, NC, clay soil in late fall to drop an unattractive bulb into a hole, only to cover it up and conceal backbreaking labor, is just not fun. But the fun comes later. Whether the residents live at the Hospice & Palliative Care of Greensboro, are hospice-appropriate in a long-term care setting, or are not within the final days of their lives, the goals for activities are the same: improving quality of life, offering opportunities for regaining control, transferring roles from care receiver to caregiver (of plants), and enabling those with limitations to continue to participate in worthwhile activities. Fresh flowers bring life into a facility where some of the residents have little chance to experience it otherwise. Using flowers at any time of year offers an invitation to socialize, the opportunity for control in a restricted setting, sensory awareness, and perhaps, a chance to experience pleasure and joy in the reality of severe limitations.

**14. Jiska Cohen-Mansfield, Steven Lipson, "To hospitalize or not to hospitalize? That is the question: An analysis of decision making in the nursing home," *Behavioral Medicine* 32, no.2 (2006):64. (7 pages)**

The authors examined the processes and factors that influence physicians' decision-making processes as regarding hospitalization of nursing home residents. In a large nonprofit nursing home, six full-time male physicians and one female nurse practitioner completed questionnaires that described the medical decision-making process for 52 nursing home residents for whom hospitalization was considered. The questionnaire covered the following topics: medical event description, the decision-making process, considerations in making treatment decisions, and the role of advance directives. Hospitalized residents had fewer treatments considered and fewer treatments chosen than those who were not hospitalized. Residents with fractures were the most commonly hospitalized residents, whereas residents in frailer condi-

tions, with breathing problems, and for whom the physician considered quality of life to be most important were less likely to be hospitalized. The results of this study clarify the complexity of factors affecting the decision-making process and suggest a methodology that may assist in discerning those factors in the future.

**15. Cathleen Colón-Emeric, Anna Schenck, Joel Gorospe, Jill McArdle, Lee Dobson, Cindy DePorter, and Eleanor McConnell, “Translating evidence-based falls prevention into clinical practice in nursing facilities: Results and lessons from a quality improvement collaborative.”**

Objectives: To describe the changes in process of care before and after an evidence-based fall reduction quality improvement collaborative in nursing facilities.

Design: Natural experiment with nonparticipating facilities serving as controls.

Setting: Community nursing homes.

Participants: Thirty-six participating and 353 nonparticipating nursing facilities in North Carolina.

Intervention: Two in-person learning sessions, monthly teleconferences, and an e-mail discussion list over 9 months. The change package emphasized screening, labeling, and risk-factor reduction.

Measurements: Compliance was measured using facility self-report and chart abstraction (n=832) before and after the intervention. Fall rates as measured using the Minimum Data Set (MDS) were compared with those of nonparticipating facilities as an exploratory outcome.

Results: Self-reported compliance with screening, labeling, and risk-factor reduction approached 100%. Chart abstraction revealed only modest improvements in screening (51% to 68%,  $p<0.05$ ), risk-factor reduction (4% to 7%,  $p=0.30$ ), and medication assessment (2% to 6%,  $p=0.34$ ). There was a significant increase in vitamin D prescriptions (40% to 48%,  $p=0.03$ ) and decrease in sedative-hypnotics (19% to 12%,  $p=0.04$ ) but no change in benzodiazepine, neuroleptic, or calcium use. No significant changes in proportions of fallers or fall rates were observed according to chart abstraction (28.6% to 37.5%,  $p=0.17$ ), MDS (18.2% to 15.4%,  $p=0.56$ ), or self-report (6.1–5.6 falls/1,000 bed days,  $p=0.31$ ).

Conclusion: Multiple-risk-factor reduction tasks are infrequently implemented, whereas screening tasks appear more easily modifiable in a real-world setting. Substantial differences between self-reported practice and medical record documentation require that additional data sources be used to assess the change-in-care processes resulting from quality improvement programs. Interventions to improve interdisciplinary collaboration need to be developed.

**16. Richard A Del Rio, Myla Goldman, BK Kapella, Loreto Sulit, Patrick K Murray, “Accuracy of Minimum Data Set diagnoses in describing recent hospitalization at acute care facilities,” *Journal of the American Medical Directors Association* 7, no.4 (2006):212-218. (7 pages)**

Evaluated the accuracy of the Minimum Data Set (MDS) diagnosis variables with respect to the diagnoses for recent hospitalization from Medicare claims data. Data for 11 diagnoses listed in the MDS for 17,294 residents aged 65 and older (mean age 79) admitted from an acute care facility during 2000 to 945 skilled nursing facilities in Ohio were compared with Medicare hospital discharge claims. Each MDS diagnosis was compared with the primary diagnosis, the list of secondary diagnoses, and the Diagnosis Related Group (DRG). Claims diagnoses were listed in the MDS with an average frequency of 79% for the primary diagnosis, 66% for any diagnosis, and 71% for the DRG. MDS diagnoses were listed as the primary diagnosis, any diagnosis, and DRG with an average frequency of 20%, 62%, and 19%, respectively, with only hip fracture listed more than 80% of the time. Results suggest that the sensitivity of the MDS for listing diagnoses from recent hospitalization appears good for most diagnoses. However, except for hip fracture, the MDS has poor predictive value with regard to the primary reason for the preceding hospitalization.

**17. B Dewar and J Hockley, "Bringing About Change in Care Homes: An Action Research Study on End of Life Care," *Gerontologist* 44, no.1 (2004):671. (1 page)**

An abstract of a study by Dewar and Hockley that describes the implementation and concurrent evaluation of implementing an integrated care pathway for end of life care in eight volunteering nursing homes is presented. It is argued that creative methodologies need to be developed to bridge the gap between research and practice in palliative care in care homes.

**18. Aram Dobalian, "Advance care planning documents in nursing facilities: Results from a nationally representative survey." (Los Angeles, CA: Center of Excellence for the Study of Health Care Provider Behavior, Sepulveda Ambulatory Care Center and Nursing Home, US Department of Health Services, School of Public Health, University of California, 2005). Available online.**

This study assessed clinical, demographic, facility, and regional factors associated with documented do-not-resuscitate (DNR) orders, feeding/medication/other treatment (FMT) restrictions, and living wills among nursing facility residents. Using the Nursing Home Component of the 1996 Medical Expenditure Panel Survey, a nationally representative sample of 815 facilities and 5899 residents, three separate multivariate logistic regression models were developed. DNR orders were more prevalent among residents aged 75+ and those with severe cognitive impairment, dementia, emphysema, and cancer, but less common among African Americans and Latinos than whites. Residents with living children were more likely to have DNR orders. Latinos were less likely to have FMT restrictions. Living wills were more common among residents aged 75+ and those with psychiatric/mood disorders and heart disease, but less prevalent among African Americans. Residents with less social engagement and household incomes below 400% of the Federal Poverty Level were less likely to have a living will. Residents with Medicaid as their largest payer were less likely to have an advance care plan than those with Medicare or other payment mechanisms. To increase the use of advance care plans, interventions should focus on groups with less social engagement and lower household income.

**19. A Dobalian, "Nursing facility compliance with do-not-hospitalize orders, *Gerontologist* 44, no.2 (2004):159-65.**

Purpose: This study sought to determine whether nursing homes comply with residents' do-not-hospitalize (DNH) orders prohibiting inpatient hospitalization.

Design and Methods: With the use of data from the nationally representative 1996 Nursing Home Component of the Medical Expenditure Panel Survey, a multivariate logistic regression model was developed.

Results: Three percent of residents had DNH orders. These residents were half as likely to be hospitalized. Residents in not-for-profit or public facilities were less likely to be hospitalized than those in for-profit homes. Hospitalization was more likely among men, racial or ethnic minorities, those with more diagnosed health conditions, and those in facilities in the South compared with those in the Midwest. Hospitalized residents with DNH orders had no limitations of activities of daily living, were not located in hospital-based nursing homes, were less likely to be in a for-profit facility, and were sicker than non-hospitalized residents with DNH orders.

Implications: Improved education regarding advance directives, particularly DNH orders, is necessary for health care practitioners and patients. More consistent and rigorous policies should be implemented in nursing facilities.

Facility and county effects on racial differences in nursing home quality indicators\*

**20. John S Doebler, Martha L Henderson, Laura C Hanson, and Kimberly S Reynolds. *Improving nursing home care of the dying: A training manual for nursing home staff.* (New York: Springer Publishing Company, 2003). (216 pages)**



**21. Christopher Donoghue and Nicholas G Castle, “Voluntary and involuntary nursing home staff turnover,” *Research on Aging* 28, no.4 (2006)454-472. (19 pages)**

Identified nursing home characteristics associated with voluntary and involuntary turnover among formal caregivers (registered nurses, licensed practical nurses, and nurses aides) in Missouri, Texas, Connecticut, and New Jersey. A total of 354 questionnaires returned from facilities were merged with data from the 2004 Online Survey, Certification and Recording system. Voluntary and involuntary turnover rates were determined by dividing the total number of terminations over a six-month period by the number of full-time staff members for each of the employee categories. Multinomial logistic regression analysis was utilized to determine whether organizational characteristics were related to a greater probability of high or low levels of voluntary and involuntary turnover. A higher ratio of nurses to beds, a smaller number of quality-of-care deficiencies, and a smaller proportion of residents using Medicaid were all associated with lower voluntary turnover but higher involuntary turnover. Results suggest that controlling turnover is a complex process that may involve monitoring the organizational levels not only of voluntary separations but also of involuntary terminations.

**22. Catherine E DuBeau, Samuel E Simon, and John N Morris, “The effect of urinary incontinence on quality of life in older nursing home residents.”**

Objectives: To determine whether nursing home residents with urinary incontinence (UI) have worse quality of life (QoL) than continent residents, whether the relationship between UI and QoL differs across strata of cognitive and functional impairment, and whether change in continence status is associated with change in QoL.

Design: Retrospective cohort study using a Minimum Data Set (MDS) database to determine cross-sectional and longitudinal (six-month) associations between UI and QoL.

Setting: All Medicare- or Medicaid-licensed nursing homes in Kansas, Maine, Mississippi, New York, and South Dakota during 1994 to 1996.

Participants: All residents aged 65 and older, excluding persons unable to void or with potentially unstable continence or QoL status (recent nursing home admission, coexistent delirium, large change in functional status, comatose, near death).

Measurements: UI was defined as consistent leakage at least twice weekly over 3 months and continence as consistent dryness over three months. QoL was measured using the validated MDS-derived Social Engagement Scale.

Results: Of 133,111 eligible residents, 90,538 had consistent continence status, 58,850 (65%) of whom were incontinent. UI was significantly associated with worse QoL in residents with moderate cognitive and functional impairment. New or worsening UI over 6 months was associated with worse QoL (odds ratio=1.46, 95% confidence interval=1.36–1.57) and was second only to cognitive decline and functional decline in predicting worse QoL.

Conclusion: This is the first study to quantitatively demonstrate that prevalent and new or worsening UI decreases QoL even in frail, functionally and cognitively impaired nursing home residents. These results provide a crucial incentive to improve continence care and quality in nursing homes and a rationale for targeting interventions to those residents most likely to benefit.

**23. Sharon E Engel, Dan K Kiely, and Susan L Mitchell, “Satisfaction with end-of-life care for nursing home residents with advanced dementia.” *Journal of the American Geriatrics Society* 54, no.10 (2006):1567-1572. (6 pages)**

Identified factors associated with care satisfaction for health care proxies (HCPs) of nursing home (NH) residents with advanced dementia. A total of 148 NH residents aged 65 and older (mean age 85.0) with advanced dementia from 13 NHs in Boston, Massachusetts, were selected based on their Cognitive Performance Score of 5 or 6, indicating advanced dementia. Their formally designated HCPs (mean age 59.1) completed interviews containing the Satisfaction With Care at the End of Life in Dementia (SWC-EOLD) scale (range 10-40; higher scores

indicate greater satisfaction). The mean SWC-EOLD score was 31.0. Variables associated with greater satisfaction were more than 15 minutes discussing advance directives with a care provider at the time of NH admission, greater resident comfort, care in a specialized dementia unit, and no feeding tube. Results suggest these modifiable factors of care in a specialized dementia unit may improve satisfaction with care in advanced dementia.

- 24. Mary Ersek and Betty R Ferrell, "Palliative care nursing education: Opportunities for gerontological nurses," *Journal of Gerontological Nursing* 31, no.7 (2005):45. (7 pages)**  
Approximately 80% of Americans who die each year are 65 or older. Increasingly, gerontological nurses are asked to deliver high quality end-of-life care. Studies, however, have identified deficiencies in the delivery of care to older adults who are dying—particularly those who die in nursing homes. Enhancing nursing education and training in end-of-life care is one strategy proposed as a remedy for inadequate care for nursing home residents who are dying. This article reviews the current status of end-of-life nursing home care, describes the philosophy and components of quality palliative care, and provides information about opportunities and resources for educating gerontological nurses in end-of-life care.
- 25. Stacy M Fischer, Wendolyn S Gozansky, Angela Sauaia, Sung-Joon Min, Jean S. Kutner and Andrew Kramer, "A practical tool to identify patients who may benefit from a palliative approach: The CARING criteria," *Journal of Pain and Symptom Management* 31, no.4 (2006):285-292.**  
Palliative care is often offered only late in the course of disease after curative measures have been exhausted. To provide timelier symptom management, advance care planning, and spiritual support, we propose a simple set of prognostic criteria that identifies persons near the end of life. In this retrospective cohort study of five prognostic indicators, the CARING criteria (Cancer, Admissions  $\geq 2$ , Residence in a nursing home, Intensive care unit admit with multi-organ failure,  $\geq 2$  Non-cancer hospice Guidelines), logistic regression modeling demonstrated high sensitivity and specificity for mortality at 1 year (c statistic  $> 0.8$ ). A simple set of clinically relevant criteria applied at the time of hospital admission can identify seriously ill persons who have a high likelihood of death in one year and, therefore, may benefit the most from incorporating palliative measures into the plan of care.
- 26. LL Franklin, BM Ternstedt, and L Nordenfelt. "Views on dignity of elderly nursing home residents," *Nursing Ethics* 13, no.2 (2006):130.**  
Discussion about a dignified death has almost exclusively been applied to palliative care and people dying of cancer. As populations are getting older in the western world and living with chronic illnesses affecting their everyday lives, it is relevant to broaden the definition of palliative care to include other groups of people. The aim of the study was to explore the views on dignity at the end of life of 12 elderly people living in two nursing homes in Sweden. A hermeneutic approach was used to interpret the material, which was gathered during semi-structured interviews. A total of 39 interviews were transcribed. The analysis revealed three themes: (1) the unrecognizable body; (2) fragility and dependency; and (3) inner strength and a sense of coherence.
- 27. Anthony Nicholas Galanos. "Sick to Death and Not Going to Take It Anymore! Reforming Health Care for the Last Years of Life/Physician-Assisted Dying: The Case for Palliative Care and Patient Choice," *Contemporary Gerontology* 11, no.4 (2005):159. (4 pages)**  
The books *Sick to Death and Not Going to Take It Anymore!: Reforming Health Care for the Last Years of Life*, by Joanne Lynn, and *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice*, edited by Timothy E. Quill and Margaret P. Battin, are reviewed.



28. **Thomas Edward Gass, *Nobody's Home: Candid Reflections of a Nursing Home Aide (The Culture and Politics of Health Care Work)* (Ithaca, NY: Cornell University Press, 2005) 189 pp. Reviewed in *Journal of the American Medical Association* no.295 (2006):2188-2189.**

There are at least two certainties in addition to taxes and death: no one wants to be a nursing home patient, and few people want to work in a nursing home. Yet 40% of those who turn 65 years will spend at least some time as nursing home patients, and 250,000 more nursing aides are needed to provide their care. These certainties arise from a multitude of problems with our present system of nursing home care, which have been, are, and will continue to be addressed (with a variable degree of success) through regulatory channels and practice innovation. This attention notwithstanding, one of the most important components of nursing home care cannot be remedied by Big Brother. That component is at the core of Thomas Edward Gass' *Nobody's Home: Candid Reflections of a Nursing Home Aide: the relationships between the patients who reside in nursing homes and those who attend to their intimate daily care.*

Sheryl Zimmerman, PhD, Reviewer, Cecil G. Sheps Center for Health Services Research and School of Social Work, University of North Carolina at Chapel Hill

29. **Charles E Gessert, Irina V Haller, Robert L Kane, and Howard Degenholtz, "Rural-urban differences in medical care for nursing home residents with severe dementia at the end of life," *Journal of the American Geriatrics Society* 54, no.8 (2006): 1199.**

To identify factors associated with the use of selected medical services near the end of life in cognitively impaired residents of rural and urban nursing homes. Retrospective cohort study using Centers for Medicare and Medicaid Services administrative data for 1998 through 2002. Minnesota and Texas nursing homes. Nursing home residents aged 65 and older with severe cognitive impairment that subsequently died during 2000/01. Minimum Data Set and Medicare Provider Analysis and Review, Hospice, and Denominator files were used to identify subjects and to assess medical service use. U.S. Department of Agriculture metro/non-metro continuum county codes defined rural (codes 6-9) and urban (codes 0-2) nursing homes. Nursing home residents with hospice or health maintenance organization benefits were excluded. Use of hospital services at the end of life was adjusted for use of corresponding services before the last year of life. Outcome variables were feeding tube use, any hospitalization, more than 10 days of hospitalization, and intensive care unit (ICU) admission. The population included 3,710 subjects (1,886 rural, 1,824 urban). In multivariable logistic regression analyses (all  $p < 0.05$ ), feeding tube use was more common in urban nursing home residents, whereas rural nursing home residents were at greater risk for hospitalization.

Conclusion: Rural residence was also associated with lower risk of more than 10 days of hospitalization and ICU admission. Non-white race and stroke were associated with higher use of all services.

30. **Jan Greene, "Circle of Life Awards 2006," *Hospitals & Health Networks* 80, no.8 (2006)44. (4 pages)**

As more American health care organizations adopt palliative care programs to reduce pain and suffering at the end of life, they bump into problems with reimbursement, understanding of palliative care's meaning and a fear of death common in US culture. And yet, innovative thinkers in all types of health care settings are finding ways around those problems, often by blurring the traditional boundaries between one kind of care and another. The American Hospital Association recognizes these innovators annually with the Circle of Life Award, which this year goes to three winners that each receive \$25,000 and four organizations that receive citations of honor. The three winners, which include Continuum Hospice Care, New York City, St. Joseph Mercy Oakland Hospital, Pontiac, MI, and Fairview Health Services, Minneapolis, are presented.

- 31. Korbin Liu, Joshua M Wiener, and Marlene R Niefeld. "End of life Medicare and Medicaid expenditures for dually eligible beneficiaries," *Health Care Financing Review* 27, no.4 (2006)95. (15 pages)**

In 1995, combined Medicare and Medicaid spending in the last year of life for dually eligible beneficiaries was more than \$40,000 per beneficiary. Medicaid's share, primarily for long-term care (LTC), constituted about 40% of the total. Beneficiaries under age 65, Black persons, and individuals who died in a hospital had higher than average expenditures. The vast majority (86%) received some form of supportive services (nursing home, home care, hospice services). It is critical that policy deliberations consider both acute and LTC use concurrently because of their extensive use by dually eligible beneficiaries, as well as the interaction of the two funding sources (Medicare and Medicaid) that cover them.

- 32. Martha L Henderson, Laura C Hanson, and Kimberly S Reynolds, *An end-of-life care curriculum for nursing home staff: Improving nursing home care of the dying: A training manual for nursing home staff.* (New York: Springer Publishing Company, 2003) 216 pages. Reviewed by James P Budis in *Journal of Pain and Symptom Management* 26, no.6 (2003):1148-1149.**

- 33. N Hodgson, "Palliative care services in Pennsylvania nursing homes." *Gerontologist* 44, no.1 (2004):548. (1 page)**

There is a growing policy interest in improving the quality of care provided at the end of life in America. At the same time, there is continued interest in improving the quality of care provided in one of the more common end-of-life settings—the nursing home. Palliative care is well recognized as the most cost effective and foremost practice to provide for a dignified death free from unnecessary suffering. Although palliative care is increasingly common in hospice and acute care settings, regulatory, financial and educational barriers often bar nursing home residents from access to palliative care services. The purpose of the Palliative Care Services in Pennsylvania Nursing Homes (PCSPNH) Study was to identify and describe existing palliative care services within nursing homes in Pennsylvania. The study consisted of two components: 1) an extensive review of the existing literature, and 2) a survey of nursing home administrators. The survey was designed so that the sample of administrators was representative of the entire state, its diverse geographic regions and its urban and rural communities. It was distributed via e-mail to 150 long-term care administrators, using a mailing list consisting of contact persons from the Commonwealth's Directory of Nursing homes. Responses to survey findings will be grouped and defined as follows: 1) basic characteristics of palliative care services; 2) characteristics of administrative and institutional support; 3) characteristics of training and research. Supported by the Pennsylvania Department of Health Bureau of Health Statistics and Research.

- 34. Diane E Hoffmann and Anita J Tarzian. "Dying in America: An examination of policies that deter adequate end-of-life care in nursing homes," *Journal of Law, Medicine & Ethics* 33, no.2 (2005):294. (16 pages)**

Hoffmann and Tarzian examine current U.S. health care policies and government practices that deter appropriate end-of-life care, focusing on the use of hospice services for dying nursing home patients. They conclude that hospice and nursing home regulations, reimbursement for hospice and nursing homes, and enforcement of the fraud and abuse rules collude to "chill" utilization of hospice by nursing homes and result in inadequate end-of-life care for many nursing home patients. They further argue that these policies and practices have at their roots a number of questionable assumptions and call for a shift in existing paradigms affecting care to this group and a realigning of incentives among these various government policies to achieve consistent policy goals.

35. **Janice K. Horner, Laura C. Hanson, Deborah Wood, Andrew G. Silver and Kimberly S. Reynolds, "Using quality improvement to address pain management practices in nursing homes," *Journal of Pain and Symptom Management* 30, no.3 (2005): 271-277.** The objective of this study was to test whether a quality improvement intervention can improve pain management in nursing homes. Experts in quality improvement and clinical pain management provided nursing home staff leaders with feedback on pain quality indicator data, education in pain management, and technical assistance to apply the Plan-Do-Study-Act model of quality improvement. Trained abstractors completed structured chart audits at baseline and five months to capture quality indicator data related to pain assessment and treatment. Residents in pain who underwent pain assessments increased from 8% to 29% ( $p < 0.001$ ). Residents receiving non-pharmacological pain treatments increased from 31% to 42% ( $p = 0.010$ ), but pain medication use did not change. Among residents with daily moderate or excruciating pain, complete pain assessment was associated with increased probability of pain medication use. Quality improvement is a promising method to improve pain management in nursing homes.
36. **"Caregiving in America," International Longevity Center—USA Report (September 2006, pdf format, 81 pages).**  
[http://www.ilcusa.org/\\_lib/pdf/Caregiving%20in%20America%20Final.pdf](http://www.ilcusa.org/_lib/pdf/Caregiving%20in%20America%20Final.pdf)  
 Press Release:  
[http://www.ilcusa.org/\\_lib/pdf/Caregiving%20In%20America%20Report%20Press%20Release.pdf](http://www.ilcusa.org/_lib/pdf/Caregiving%20In%20America%20Report%20Press%20Release.pdf)
37. **Anthony F Jerant, Rahman S Azari, Thomas S Nesbitt, Adrienne Edwards-Goodbee, and Frederick J Meyers. "The Palliative Care in Assisted Living (PCAL) pilot study: Successes, shortfalls, and methodological implications." *Social Science & Medicine* 62, no.1 (2006):199.** Troubling deficits exist in palliative care (PC) of older adults under the prevailing "terminal care"-oriented model. We previously described a PC model—TLC—that provides a blueprint for remedying these shortfalls. In this model, PC is envisioned as Timely and Team-oriented, Longitudinal, and Collaborative and Comprehensive. We present results of the Palliative Care in Assisted Living pilot, comparing two TLC model-based, facility delivered interventions for improving the PC of elderly assisted living residents in Sacramento, California, a growing and under-researched population. The less intensive intervention involved one assessment followed by a PC improvement recommendation letter to the resident, family member, primary provider, and facility staff, while the more intensive intervention involved assessments and letters every three months. Primary outcomes were SF-36 Physical (PCS) and Mental (MCS) Component scores and recommendation adherence. Eighty-one subjects enrolled (mean age 85), 58 in the more and 23 in the less intensive group. A loved one attended 56% of baseline assessments. Most subjects expressed a preference for maintaining current quality of life over prolonging life at reduced quality. None were eligible for hospice care. A total of 418 recommendations (mean 5.1 per subject) were generated concerning symptoms, mood, functional impairments, and advance directives. We found no significant differences in recommendation adherence between more (42%) and less (44%) intensive groups, and no significant changes in PCS and MCS scores within or between groups. However, a loved one's attendance of the baseline assessment was associated with improved PCS scores ( $p = 0.04$ ). Our pilot study had methodological limitations that could account for the lack of significant outcome effects. In this context, and given the myriad unmet PC needs we detected, interventions based on the TLC model might allow delivery of timely PC to assisted living residents not eligible for hospice care. Further studies exploring the TLC model appear warranted.

- 38. Sandra H Johnson, "Making room for dying: end of life care in nursing homes," *Hastings Center Report, Special Report 35, no.6 (2005):S37-S41. (5 pages)***  
 The author argues that understanding that over 20% of older Americans die in nursing homes ought to drive society to improve end-of-life care. Suggests that the rehabilitative expectations, captured and reinforced in nursing home regulation, skew nursing home care models away from care of the dying. Argues that efforts to make room for the dying patient require a review of standards and adoption of changes to facilitate the appropriate level and type of care. Notes that the challenge is to encourage the regulatory system to accept the process of dying, with its accompanying physical and mental deterioration, to exercise restraint in the use of interventions, and to do so without creating a shield for neglect. Discusses three fundamental assumptions in the current structure for end-of-life decision-making that are ill-suited to the nursing home environment: "end of life care" is synonymous with "care for the dying," the patient is the only person whose autonomy or well-being has moral significance, and there should be a presumption in favor of life-sustaining treatment. Argues that it is time to consider whether the presumption in favor of life-sustaining treatment should be changed to a presumption in favor of care that provides comfort, relieves suffering, or promotes activities of daily living.
- 39. Katherine R Jones, Regina Fink, Evelyn Hutt, Carol Vojir, Ginnette A Pepper, Jill Scott-Cawiezell and B Karen Mellis, "Measuring pain intensity in nursing home residents," *Journal of Pain and Symptom Management, 30 no.6, (2005):519-527.***
- 40. Rosalie A Kane, "Definition, measurement, and correlates of quality of life in nursing homes: Toward a reasonable practice, research, and policy agenda," *Gerontologist 43 (2003):28.***  
 Purpose: This article identifies challenges in defining, measuring, and studying quality of life of nursing home residents  
 Design and Method: A theoretical analysis was conducted based on literature and the author's own large-scale studies of quality of life of nursing home residents.  
 Results: Measuring quality of life is a relatively low priority in nursing homes because of focus on markers of poor quality of care, pervasive sense that nursing homes are powerless to influence quality of life, and impatience with research among those dedicated to culture change. The research argues that the resident voice must be sought in reaching operational definitions for quality of life and as reporters on the quality of their own lives, and that resident burden is a spurious concern that should not deter direct interviews with residents. Five challenges in measuring quality of life were identified: (a) designing questions with appropriate response categories and time frames, (b) developing a sampling strategy, (c) aggregating information at the individual and facility level, (d) validating what are ultimately subjective constructs, and (e) developing an approach using observations and proxies to assess quality of life for approximately 40% of the residents who will be impossible to interview.  
 Implications: although residents' perceived quality of life is partly a product of their health, social supports, and personalities, nursing homes can directly influence quality of life through their policies, practices, and environments, and, indirectly, through their approaches to family and community. A research agenda is needed, which includes both methodological research and studies of the correlates of quality of life.
- 41. Bitu A Kash, Nicholas G Castle, George S Naufal, and Catherine Hawes, "Effect of staff turnover on staffing: A closer look at registered nurses, licensed vocational nurses, and certified nursing assistants," *Gerontologist 46, no.5 (2006):609. (11 pages)***  
 Purpose: We examined the effects of facility and market-level characteristics on staffing levels and turnover rates for direct care staff, and we examined the effect of staff turnover on staffing levels.  
 Design and Methods: We analyzed cross-sectional data from 1,014 Texas nursing homes. Data

were from the 2002 Texas Nursing Facility Medicaid Cost Report and the Area Resource File for 2003. After examining factors associated with staff turnover, we tested the significance and impact of staff turnover on staffing levels for registered nurses (RNs), licensed vocational nurses (LVNs) and certified nursing assistants (CNAs).

Results: All three staff types showed strong dependency on resources, such as reimbursement rates and facility payer mix. The ratio of contracted to employed nursing staff as well as RN turnover increased LVN turnover rates. CNA turnover was reduced by higher administrative expenditures and higher CNA wages. Turnover rates significantly reduced staffing levels for RNs and CNAs. LVN staffing levels were not affected by LVN turnover but were influenced by market factors such as availability of LVNs in the county and women in the labor force.

Implications: Staffing levels are not always associated with staff turnover. We conclude that staff turnover is a predictor of RN and CNA staffing levels but that LVN staffing levels are associated with market factors rather than turnover. Therefore, it is important to focus on management initiatives that help reduce CNA and RN turnover and ultimately result in higher nurse staffing levels in nursing homes.

**42. D Casarett, J Karlawish, K Morales, R Crowley, et al, "Improving the use of hospice services in nursing homes: A randomized controlled trial," *Journal of the American Medical Association* 294, no.2 (2005):211.**

Context: Hospice care may improve the quality of end-of-life care for nursing home residents, but hospice is underutilized by this population, at least in part because physicians are not aware of their patients' preferences.

Objective: To determine whether it is possible to increase hospice utilization and improve the quality of end-of-life care by identifying residents whose goals and preferences are consistent with hospice care.

Design, Setting, and Participants: Randomized controlled trial (December 2003-December 2004) of nursing home residents and their surrogate decision makers (n=205) in 3 US nursing homes.

Intervention: A structured interview identified residents whose goals for care, treatment preferences, and palliative care needs made them appropriate for hospice care. These residents' physicians were notified and asked to authorize a hospice informational visit.

Main Outcome Measures: The primary outcome measures were (1) hospice enrollment within 30 days of the intervention and (2) families' ratings of the quality of care for residents who died during the six-month follow-up period.

Results: Of the 205 residents in the study sample, 107 were randomly assigned to receive the intervention, and 98 received usual care. Intervention residents were more likely than usual care residents to enroll in hospice within 30 days (21/107 [20%] vs. 1/98 [1%];  $p < 0.001$  [Fisher exact test]) and to enroll in hospice during the follow-up period (27/207 [25%] vs. 6/98 [6%];  $p < 0.001$ ). Intervention residents had fewer acute care admissions (mean: 0.28 vs 0.49;  $p = 0.04$  [Wilcoxon rank sum test]) and spent fewer days in an acute care setting (mean: 1.2 vs 3.0;  $p = 0.03$  [Wilcoxon rank sum test]). Families of intervention residents rated the resident's care more highly than did families of usual care residents (mean on a scale of 1-5: 4.1 vs 2.5;  $p = 0.04$  [Wilcoxon rank sum test]).

Conclusion: A simple communication intervention can increase rates of hospice referrals and families' ratings of end-of-life care and may also decrease utilization of acute care resources.

**43. Betsy Kemeny, Iris F Boettcher, Richard P DeShon and Alan B Stevens, "Using experiential techniques for staff development: liking, learning, and doing." *Journal of Gerontological Nursing* 32, no.8 (2006):9-14. (6 pages)**

Evaluated whether experiential training techniques used in an Alzheimer's disease research project are acceptable, appealing to staff, and effective in increasing knowledge in person-centered care (PCC) skills among certified nursing assistants (CNAs) and nurses in nursing



homes. A total of 77 nursing staff (41 CNAs and 36 nurses) participated in the study. All participants were exposed to a formal training intervention and informal coaching sessions during a 5-week period. Training content included knowledge of dementia and a PCC view of care, communication skills, skills for individualizing care, and knowledge of and skills for responding to need-driven behaviors. Experiential techniques such as role plays and simulation were chosen for learning objectives involving interpersonal interaction. Training sessions were well received by CNAs and nurses throughout the training and 2 months post-training. The role plays and exercises for individual sessions were also well received. Questions testing participants' knowledge of PCC were asked after each session and 2 months after training. The percentage correct during the training and 2 months post-training indicate that both CNAs and nurses learned and retained most of the training material, although nurses did better on written tests of knowledge of PCC than CNAs. CNAs more often reported feeling comfortable using PCC techniques than nurses, perhaps because PCC may be perceived as more relevant to direct resident care and the role of CNAs.

**44. Jeanie S Kayser-Jones, Alison E Kris, Christine A Miaskowski, William L Lyons, and Steven M Paul, "Hospice care in nursing homes: Does it contribute to higher quality pain management?" *Gerontologist* 46, no.3 (2006):325-333. (9 pages)**

Examined pain management among hospice and non-hospice residents of two nursing homes. Data came from participant observation, interviews, event analysis, and chart review of 42 hospice and 65 non-hospice residents (mean age 75.10 and 81.74, respectively). The Medication Quantification Scale was used to account for the prescription and administration of all analgesic medications. Care of residents was observed several times a week from the time they were identified as being terminally ill until they died (a time period ranging from one day to 15 months, mean 45 days). Pain measurement was noted based on resident's report (none, mild, moderate, or severe), observations of pain indicators, and interviews with family and nursing staff. Although 72% of residents experienced pain, no significant differences were found in the proportion of hospice versus non-hospice residents who had been prescribed opioids and co-analgesics and whose medication was administered around the clock or as needed. Limited physician availability, lack of pharmacologic knowledge, and limitations of nursing staff hindered pain management in both groups of residents. The data suggest that neither the physicians nor the nurses had adequate expertise in pain management. Implications are that although hospice care is of some benefit, pain management and high-quality end-of-life care is dependent on the context in which it is provided. Given that between 1991 and 2001, Medicare expenditures for nursing home-based hospice care increased from \$8.6 million to \$21.8 million, the effectiveness of hospice-care programs in nursing homes warrants further study.

**45. Jeanie Kayser-Jones, Ellen Schell, William Lyons, Alison E Kris, et al, "Factors that influence end-of-life care in nursing homes: The physical environment, inadequate staffing, and lack of supervision," *Gerontologist* 43 (2003):76.**

Purpose: This study investigated the physical environment and organizational factors that influenced the process of providing care to terminally ill nursing home residents. Design and Methods: participant observation, interviews, and event analysis were used to obtain data in two proprietary facilities. Results: the physical environment was not conducive to end-of-life care. The rooms were crowded, there was little privacy, and the facilities were noisy. Inadequate staffing and lack of supervision were among the most significant organizational factors that influenced care. Often, residents did not receive basic care, such as bathing, oral hygiene, adequate food and fluids, and repositioning. A consequence of inadequate staffing was the development of pressure ulcers; 54% of the residents had pressure ulcers; 82% of these residents died with pressure ulcers. Implications: findings suggest that the nursing home environment in these two facilities, as now structured, is an inappropriate setting for end-of-life care.

- 46. Martin Kitchener, James H Swan, and Charlene Harrington, "Medicaid nursing facility utilization," *Research on Aging* 28, no.4 (2006):493-514. (22 pages)**  
 Investigated the impact of national cost-control policies and resident, facility, and county market predictors for Medicaid nursing facility (NF) utilization. Data were derived from the California Office of Statewide Health Planning and Development cost and utilization reports from 1995 to 2000 in order to analyze data trends in Medicaid NF participants, days of care, and expenditures. The percentage of Medicaid days of care (% MDOC) was examined for 1,157 facilities in the 1995 set, and 1,144 in 2000, with a total of 6,936 NF observations over the six-year study period. Resident characteristics involved need, ethnicity, and gender. Facility enabling factors included facility size, ownership, sub-acute beds, specialized programs, chain membership, Medicaid rate, and admissions of residents funded by other providers. Results showed that although statewide Medicaid NF participants, expenditures and % MDOC remained stable, Medicaid market segmentation persisted, with program participants distributed unevenly among facilities. Factors associated positively with facility % MDOC were the proportion of minority residents, a larger facility size, for-profit status, the percentage of aged black persons in the county, and market concentration. The factors associated negatively with % MDOC were the percentages of resident men, residents aged 85 or older, residents with Alzheimer's disease, Medicaid reimbursement rates, and county wealth.
- 47. Debra Lacey, "End-of-life decision making for nursing home residents with dementia: A survey of nursing home social services staff," *Health & Social Work* 31, no.3 (2006):189 (11 pages)**  
 The purpose of this survey was to describe nursing home social services staff roles and perceptions related to end-of-life medical decision making for nursing home residents in end-stage dementia. Using a self-designed questionnaire, 138 nursing home social services staff from across New York State answered questions about advance directives, medical interventions, and comfort levels with withholding and withdrawing of treatment. Results showed a high degree of involvement in advance directive discussions, problems in the implementation of advance directives, and wide variation in comfort levels with treatment issues. Results of this study indicate areas of need for further research and training of nursing home social services staff.
- 48. Mark Loeb, Soo Chan Carusone, Ron Goeree, Stephen D Walter, Kevin Brazil, Paul Krueger, Andrew Simor, Lorraine Moss, and Thomas Marrie, "Effect of a clinical pathway to reduce hospitalizations in nursing home residents with pneumonia," *Journal of the American Medical Association* 295 (2006):2503-2510.**  
 Nursing home residents with pneumonia are frequently hospitalized. Such transfers may be associated with multiple hazards of hospitalization as well as economic costs. Objective: to assess whether using a clinical pathway for on-site treatment of pneumonia and other lower respiratory tract infections in nursing homes could reduce hospital admissions, related complications, and costs.  
 Design, Setting, and Participants: a cluster randomized controlled trial of 680 residents aged 65 years or older in 22 nursing homes in Hamilton, Ontario, Canada. Nursing homes began enrollment between January 2, 2001, and April 18, 2002, with the last resident follow-up occurring July 4, 2005. Residents were eligible if they met a standardized definition of lower respiratory tract infection. Interventions Treatment in nursing homes according to a clinical pathway, which included use of oral antimicrobials, portable chest radiographs, oxygen saturation monitoring, re-hydration, and close monitoring by a research nurse, or usual care.  
 Main Outcome Measures: Hospital admissions, length of hospital stay, mortality, health-related quality of life, functional status, and cost. Results Thirty-four (10%) of 327 residents in the clinical pathway group were hospitalized compared with 76 (22%) of 353 residents in the usual care group. Adjusting for clustering of residents in nursing homes, the weighted mean reduc-



tion in hospitalizations was 12% (95% confidence interval [CI], 5%-18%;  $p=0.001$ ). The mean number of hospital days per resident was 0.79 in the clinical pathway group vs 1.74 in the usual care group, with a weighted mean difference of 0.95 days per resident (95% CI, 0.34-1.55 days;  $p=0.004$ ). The mortality rate was 8% (24 deaths) in the clinical pathway group vs 9% (32 deaths) in the usual care group, with a weighted mean difference of 2.9% (95% CI, -2.0% to 7.9%;  $p=0.23$ ). There were no significant differences between the groups in health-related quality of life or functional status. The clinical pathway resulted in an overall cost savings of US \$1016 per resident (95% CI, \$207-\$1824) treated.

Conclusion: Treating residents of nursing homes with pneumonia and other lower respiratory tract infections with a clinical pathway can result in comparable clinical outcomes, while reducing hospitalizations and health care costs.

**49. Cindy MacQuarrie. "The MDS: Are you leaving money on the table? *Nursing Homes* 55, no.9 (2006):79. (2 pages)**

As providers are discovering every day, the Minimum Data Set (MDS) is a valuable financial reimbursement tool. Many nursing professionals have not been trained in financial matters and regulations related to health care; their education and training have focused on patient care. Flexing the Assessment Reference Date (ARD) is one method of enhancing revenue for care provided. The ARD sets the time period for collecting and reporting information about a resident's status. Being flexible in setting the ARD takes a thorough understanding of the MDS and the impact of MDS payment levels under Medicare and Medicaid, excellent communication and assessment skills, and good time-management practices. Training staff on key components of the MDS is an effective strategy. All staff should understand the MDS process, why the assessment is completed, the financial impact of clinical activities and their documentation, and how to complete their contribution to the MDS accurately.

**50. Claudine McCreadie, "Maltreatment of patients in nursing homes: There is no safe place," *Journal of Adult Protection* 8, no.3;(2006):39. (3 pages)**

McCreadie reviews *Maltreatment of Patients in Nursing Homes: There is No Safe Place* by Diana K. Harris and Michael L. Benson.

**51. Sandy Meyers, "Role of the social worker in old versus new culture in nursing homes," *Social Work* 51, no.3; (2006):273. (5 pages)**

Social workers play a crucial role in the lives of people living in nursing homes. Meyers provides several illuminating examples of ways in which social workers who work in nursing homes can contribute to the development of a culture of service delivery that moves beyond sustaining life into one of infusing life with the joy of living.

**52. Susan C Miller, George Papandonatos, Mary Fennell, and Vincent Mor. "Facility and county effects on racial differences in nursing home quality indicators," *Social Science & Medicine* 63, no.12 (2006):3046.**

This study's goal was to examine the effects of nursing home (NH) and county racial mix on quality of care in NHs. We examined quality indicator (QI) outcomes for residents in 408 urban New York nursing homes in July through September 1995. The QI outcomes studied were restraint and anti-psychotic drug use (for low and high-risk residents), and at study commencement, these QIs were being used by the Centers for Medicare and Medicaid Services to monitor the quality of care in USA Medicare and/or Medicaid-certified NHs. A hierarchical modeling approach was used to properly reflect the nesting of both residents within NHs and NHs within counties. Separate regression models were fit to the two strata of interest (Urban Non-Hispanic Whites and Urban African Americans) to test, for each race group, the effect on quality of residing in NHs and counties with higher proportions of African Americans (than state medians). Descriptive analyses found that, compared to Whites, the unadjusted restraint rate

was lower for African Americans while the antipsychotic drug rate was higher. For both race groups, multi-level analyses showed residence in for-profit NHs was associated with higher likelihoods of being restrained, and of receiving antipsychotic drugs. Also, for both race groups, residence in NHs with higher proportions of African-Americans was associated with lower likelihoods of being restrained and with higher, statistically no significant, likelihoods of receiving antipsychotic drugs. Higher NH nurse staffing ratios were associated with higher likelihoods of being restrained and with lower likelihoods of antipsychotic drug use (statistically significant for low-risk African-Americans). Findings support the notion that differential care is provided in USA NHs caring for higher proportions of African-American residents and thereby suggest intervention at the organizational level is warranted to improve QI outcomes for both race groups.

**53. Susan C Miller and Vincent Mor, "The opportunity for collaborative care provision: The presence of nursing home/hospice collaborations in the U.S.," *Journal of Pain and Symptom Management* 28, no.6 (2004)537-547.**

This study estimated the proportion of U.S. nursing homes (NHs) collaborating with Medicare hospices and identified state-level factors associated with this collaboration. Collaboration was classified as present when at least one of a NH's residents dying in July through December, 2000 received hospice. Seventy-six percent of NHs (n=12,174) had hospice collaborations, with proportions ranging from 37% in Wyoming to 96% in Florida. State-level factors associated with greater collaboration included having a lower proportion of persons 65+ residing in rural areas, lower NH occupancy and larger hospices, and Medicaid NH reimbursement which was not case-mixed and was paid directly to NHs (not to hospices) for hospice-enrolled residents. Considering the high amount of estimated NH/hospice collaboration, care provision by both NHs and hospices appears to be a potentially viable approach for providing comprehensive end-of-life care in the majority of U.S. NHs. Findings suggest the rural composition of a state as well as its policies and health care market characteristics either foster or discourage NH/hospice collaboration.

**54. Susan C Miller, Vincent Mor and Joan Teno, "Hospice enrollment and pain assessment and management in nursing homes," *Journal of Pain and Symptom Management* 26, no.3, (2003):791-799.**

This study compared pain assessment and management in the last 48 hours of life for hospice and non-hospice nursing home residents. Included were 209 hospice and 172 non-hospice residents in 28 nursing homes in six geographic areas. Hospice patients were considered short-stay (seven days or less) (n=51), or longer-stay (over seven days) (n=158). Of residents not in a hospital or a coma (n=265), 33% of non-hospice residents, 6% of short-stay and 7% of longer-stay hospice residents had no documented pain assessment (P<0.05). For those with pain documented (n=93), longer-stay hospice residents, compared to non-hospice residents, had a significantly greater likelihood of having received an opioid (adjusted odds ratio [AOR] 5.4; 95% CI 1.3, 21.7), at least twice a day (AOR 2.7; 95% CI 0.9, 7.7; p=0.07). Study results suggest that hospice enrollment improves pain assessment and management for nursing home residents; they also document the need for continued improvement of pain management in nursing homes.

**55. Christine Mueller, Greg Arling, Robert Kane, Julie Bershadsky, et al, "Nursing home staffing standards: Their relationship to nurse staffing levels," *Gerontologist* 46, no.1 (2006):74. (7 pages)**

Purpose: This study reviews staffing standards from the 50 states and the District of Columbia to determine if these standards are related to nursing home staffing levels. Design and Methods: Rules and regulations for states' nursing home staffing standards were obtained for the 50 states and the District of Columbia. Nurse staffing data were obtained from the Centers for

Medicare and Medicaid Services Online Survey, Certification, and Reporting (known as OSCAR) database. The minimum hours per resident day (HPRD) staffing standards for each state were categorized according to the following: no state-specific HPRD standard (adheres only to federal staffing guidelines); low HPRD standard ( $\leq 2.5$  HPRD); and high HPRD standard ( $> 2.5$  HPRD). A series of hierarchical linear models examined the relationships between state staffing standards and actual facility staffing (total, licensed, and certified nurse aide HPRD), using a number of covariates.

Results: The variance in facility staffing was much greater within than between states. Facilities in states with high staffing standards had somewhat higher staffing than states with no standards or low standards, whereas facility staffing in states with low standards was not significantly different from that in states with no standards. Other factors, such as resident acuity and average state Medicaid rate were also related to staffing.

Implications: State staffing standards may not be effective policy tools because they are only one of many factors that affect facility staffing levels.

**56. Dana B Mukamel, Helena Temkin-Greener, Rachel Delavan, Derick R Peterson, et al, "Team performance and risk-adjusted health outcomes in the Program of All-Inclusive Care for the Elderly (PACE)," *Gerontologist* 46, no.2 (2006):227. (11 pages)**

Purpose: The Program of All-inclusive Care for the Elderly (PACE) is a community-based program providing primary, acute, and long-term care to frail elderly individuals. A central component of the PACE model is the interdisciplinary care team, which includes both professionals and non-professionals. The purpose of this study was to examine the association between the team's overall performance and the risk-adjusted health outcomes of program enrollees.

Design and Methods: The study included interdisciplinary teams in 26 PACE programs and 3,401 individuals enrolled in them. We combined information about individuals' health, functional, and mental status from DataPACE with an overall measure of team performance. We used multivariate regression techniques to test the hypothesis that better team performance is associated with better risk-adjusted health outcomes: survival and short-term (within three months of enrollment) and long-term (within 12 months of enrollment) improvements in functional status and in urinary incontinence. Results: Team performance was significantly associated with better functional outcomes (both short and long term) and with better long-term urinary incontinence outcomes. There was no significant association with survival. Implications: This study provides empirical evidence for the relationship between team performance and patient outcomes in long-term care. It suggests that PACE programs can improve patient outcomes by improving the functioning of care teams.

**57. Janet E Neigh, "Medicare hospice benefit needs to be updated...not cut," *Caring* 25 no.3 (2006):47-51. (5 pages)**

Argues that reimbursement for the Medicare Hospice Benefit (MHB), created in 1982 to care for terminally ill cancer patients and now used for terminal patients with other diagnoses, needs to be updated to reflect changes during the last 23 years. Notes that in 1983 the average length of stay (LOS) in hospice was 70 days, and in 2003 the median LOS was 16 days; the shorter LOS increases per diem costs for each patient, resulting in hospices caring for more patients for a shorter period of time. Adds that increased costs for pharmaceuticals and pharmacotherapy have resulted in a dramatic rise in their percentage of average daily costs, from 3% in 1983 to 13% in 1999. Notes that the Bush Administration's proposed budget would result in a decrease of \$550 million over five years of MHB expenditures. Discusses the 2005 proposed Hospice Conditions of Participation that would require hospices to develop and maintain a hospice-wide, data-driven quality assessment and performance improvement program that would cover all services provided. Concludes that it is likely that the MHB will be modernized eventually to more closely reflect the needs of today's patients in the final stage of life and

that the government will focus more attention on determining the most cost-effective means of providing end-of-life care.

**58. David M Oatway. "CMS strives for accurate reimbursement," *Nursing Homes* 55, no.9 (2006):90. (2 pages)**

The Staff Time and Resource Intensity Verification (STRIVE) project, is a Centers for Medicare & Medicaid Services (CMS) study initiated in Oct 2005. STRIVE is the fourth national study of nursing home resource intensity CMS has conducted, and the first since the RUG III-based Prospective Payment System went into effect. This study will recalibrate the RUG algorithm based on current medical and nursing home practices and the resident mix. Nursing homes will need to have their software updated to support changes in the payment system. Moreover, CMS has expressed interest in improving the information technology (IT) used by nursing homes. To that end, CMS is collecting a set of clinical technology-related questions to be answered by participating nursing homes. Some additional assessment items are collected to improve the ability of RUGs to predict the resource use of residents and their care.

**59. Richard L Peck, "Training staff online," *Nursing Homes* 55, no.8 (2006):24. (2 pages)**

In-service training—a great idea, except for when it does not work. And there are several reasons why the traditional classroom setting often produces less-than-satisfying results. Scaring up a little early seed money, nursing home administrators Tamar Abell and Ben Klein put together a series of eight modules on basic issues such as restraint reduction and pressure ulcer prevention, and each introduced it to eight facilities in their respective chain operations. They were pleased to find out that computerization allowed for simple tracking of each staffer's training experience across the entire organization. Because the modules are available 24/7, they can be used flexibly. Students' test performances are tracked from a central location, where a manager can assemble reports on who was hired when, background check results, specific training experience, and test results.

**60. Jill Quadagno and Sidney M Stahl, "Challenges in nursing home care: A research agenda," *Gerontologist* 43 (2003):4.**

Abstract: Concurrent changes are occurring in the population of seniors: (a) growth in numbers and proportion in the population, (b) declines in disability, (c) the financing of extended care, (d) the intimate link found uniquely in long-term care settings between place of residence and personal care, (e) the variety of multiple locations of services provided, and (f) the personnel problems associated with nursing homes. These problems suggest the urgent need for focused research addressing solutions for America's aging population.

**61. J Rabig, W Thomas, RA Kane, LJ Cutler, and S McAlilly, "Radical redesign of nursing homes: Applying the Green House concept in Tupelo, Mississippi," *Gerontologist* 46, no.4 (2006):533.**

Purpose: We present the concept of the Green House, articulated by William Thomas as a radically changed, "deinstitutionalized" nursing home well before its first implementation, and we describe and discuss implications from the first Green Houses in Tupelo, Mississippi.

Design and Methods: Green Houses are small, self-contained houses for 10 or fewer elders, each with private rooms and full bathrooms and sharing family-style communal space, including hearth, dining area, and full kitchen. Line staff at the level of certified nursing assistants, called Shahbazim, are "universal workers," who cook meals, do laundry, provide personal care, assist with habilitation, and promote the elders' quality of life. Nurses, doctors, and other professionals comprise a visiting clinical support team for the residents and Shahbazim. Multiple Green Houses comprise a nursing home, meeting all nursing facility regulations and working within state-reimbursement levels. In 2003, four Green Houses were built on the campus of a retirement community; in June of that year, 40 residents relocated from the 140-bed nursing

home to the Green Houses, including 20 residents previously living in the locked dementia unit. Results: Experiences to date are positive for residents, family, and staff. The sponsor is converting the entire facility to Green Houses, and other providers around the country plan to implement Green House variants.

Implications: Because nursing home stock is aging, many physical plants are or soon will be slated for major rebuilding, thereby providing sponsors with an opportunity to consider Green Houses. Early experience suggests that Green Houses are feasible and that outcomes are likely to be positive, and it also suggests that there are some potential issues to overcome in such a dramatic reengineering of nursing homes.

**62. Marilyn J Rantz, Lanis Hicks, Gregory F Petroski, Richard W Madsen, et al, "Stability and sensitivity of nursing home quality indicators," *Journals of Gerontology* 59A, no.1 (2004):79.**

The issues of stability and sensitivity of indicators to actually detect differences in quality of care in nursing facilities are not only of concern to researchers, but also to public policy makers, who are reporting indicators to providers and now to consumers. A research team at the University of Missouri-Columbia completed a study that examined the cost, staffing, and quality of care information from the nursing home Minimum Data Set and Medicaid cost report large data sets with processes of care data collected from on-site participant observations of each facility.

**63. Marilyn J Rantz, Lanis Hicks, Victoria Grando, Gregory F Petroski, et al, "Nursing home quality, cost, staffing, and staff Mix," *Gerontologist* 44, no.1 (2004):24. (15 pages)**

Using a three-group exploratory study design, Rantz et al. describe the processes of care, organizational attributes, cost of care, staffing level and staff mix in a sample of Missouri homes with good, average and poor resident outcomes. Based on the results of their study, nursing homes must have leadership that is willing to embrace quality improvement and group process and see that the basics of care delivery are provided in order to achieve good resident outcomes.

**64. Jules Rosen, Vikas Mittal, Howard Degenholtz, Nick Castle, Benoit H Mulsant, Shelley Hulland, David Nace, and Fred Rubin, "Ability, incentives, and management feedback: organizational change to reduce pressure ulcers in a nursing home," *Journal of the American Medical Directors Association* 7, no.3 (2006).**

Evaluated a quality improvement (QI) process to reduce pressure ulcers (PUs) in a nursing home. All residents and staff from a not-for-profit, 136-bed nursing home in urban Western Pennsylvania participated in a 48-week, longitudinal study comparing the incidence of PUs during four consecutive 12-week periods: one baseline, one intervention, and two post-intervention periods. Despite having hired a full-time skin care nurse 1-year earlier, the PU prevalence at this facility remained above 20% (versus a national mean of 14%). The intervention consisted of three components: ability enhancement, incentivization and management feedback. To enhance ability, all staff members completed a computer-based interactive video education program on PU prevention and were mandated to use penlights to promote early detection. Incentives included \$75 for each staff member if the desired reduction in PU incidence was achieved. Management feedback provided real-time information of staff's adherence to the mandated training, responding to non-compliance with rewards for training completion and stepped discipline. Adherence to protocol, as measured by training compliance, was 100%. There was a significant reduction in the incidence of stage two or worse PUs during the intervention period; however, during the post-intervention periods, the effect was lost.



65. **Cynthia C Scalzi, Lois K Evans, Alan Barstow, Kathryn Hostvedt. "Barriers and enablers to changing organizational culture in nursing homes," *Nursing Administration Quarterly* 30, no.4 (2006): 368.**

To discuss the barriers and enablers of changing organizational culture in three nursing homes undergoing a culture change initiative, and suggest actions for program enhancement. Interview data with staff (n=64) and families (n=14) from three culture-change facilities in a larger mixed-methods pilot study were used to identify barriers and enablers. The three sites ranged from 120 to 139 beds and did not differ in staff characteristics. Barriers included exclusion of nurses from culture-change activities, perceived corporate emphasis on regulatory compliance and the "bottom line," and high turnover of administrators and caregivers. Enablers included a critical mass of "change champions," shared values and goals, resident/family participation, and empowerment at the facility level. Involve all levels of staff, residents, and community in culture-change activities. Align incentives and rewards with the new values. Empower individual homes to make decisions at the facility level. Work with corporate partners to enable rapid translation and implementation of recommendations based on the findings

66. **Richard Schamp, "Managed death in a PACE: pathways in present and advance directives," *Journal of the American Medical Directors Association* 7, no.6 (2006):339-344. (6 pages)**

Tested the effectiveness of a method of documenting present directives (PDs) and advance directives (ADs) on the rates of completion and the qualitative choices of health care wishes. A total of 160 participants (mean age 76.3) enrolled in a Program of All-Inclusive Care of the Elderly (PACE) urban community outpatient site were given the opportunity to complete the Pathways tool, a color-coded system of documenting health care wishes for both PDs and ADs. Data were obtained from medical records at baseline (before presentation of the Pathways tool) and 12 months to calculate rates of completion, proportions of qualitative choices, and compliance with wishes at death. Baseline prevalence of PDs and ADs was 77% and 36%, respectively, while do-not resuscitate (DNR) wishes were documented in 48% of PDs and 26% of ADs. After implementation of the Pathways tool, completion rates increased to 99% for both PDs and ADs. Documented DNR wishes decreased to 38% of PDs and increased to 66% of ADs. Qualitative choices for care changed toward a palliation pathway for ADs (from 9% to 53%). The rate of dying at home increased from 24% to 65%. Compliance with end-of-life wishes increased from 72% to 96%. It is concluded that the use of the Pathways tool is associated with choosing less invasive care in ADs and increased compliance with participants' wishes and deaths at home.

67. **Fredrick T Sherman and Kenneth Boockvar, "Transitional care: Governmental regulation versus provider oversight?" *Geriatrics* 61, no.7 (2006):8. (1 page)**

Results of our own nursing home administrators survey suggest that the quality of transfers from hospitals that provide geriatric care is higher than from hospitals that do not (unpublished data), suggesting that improving access to geriatric care would, among other benefits, improve transitional care. Until such systems are more widespread, creating incentives to improve transitional care may be up to accrediting and regulatory bodies, such as JCAHO (with its 2005 patient safety goal for medication reconciliation across the continuum of care).

68. **Peter C Trask, Joan M Teno and Justin Nash, "Transitions of care and changes in distressing pain," *Journal of Pain and Symptom Management* 32, no.2 (2006):104-109.**

This study employed a 22-state mortality follow-back survey to examine bereaved family members' perception of the level and pattern of distressing pain in decedents with cancer at the last two sites of care. Of the 1,578 individuals interviewed, 423 of their family members had cancer listed as the leading cause of death on the decedent's death certificate. Decedents were treated at home, hospitals, hospices, or nursing homes, with more than half of the respondents

(n=216) reporting that the decedent was at more than one site of care in the last month. Forty-two percent of decedents had distressing pain (defined as “quite a bit” or “very much”) at their second to last place of care, with 40% having distressing pain at the last place. There was some variation in the degree of change depending on the transition between the second to last and last places of care. For many individuals, however, the transition to another place of care did not result in an improvement in the level of distressing pain. No significant differences were found in the change in distressing pain by transition of care. Increased attention is needed not only on how to adequately manage pain and pain-related distress but also on how to improve pain reduction measures in transitions between health care settings at the end of life.

**69. Shirley S Travis, Marie Bernard, Sharon Dixon, William J. McAuley, Gary Loving, and Lue McClanahan, “Obstacles to palliation and end-of-life care in a long-term care facility,” *Gerontologist* 42, no.3 (2002):342. (8 pages)**

**Purpose:** This exploratory study used a set of four obstacle constructs derived from both the existing literature and our earlier work to describe the diverse end-of-life scenarios observed for a group of residents in a long-term care facility.

**Design and Methods:** Data from a retrospective chart review and both quantitative and qualitative methods of data collection and analysis were used to examine in-depth the end-of-life experiences of all nursing home residents (n=41) who died on the nursing care unit of a large continuing care retirement community during an 18-month period.

**Results:** A hierarchy of obstacles to palliation and end-of-life care seems to exist in long-term care settings that begin with the lack of recognition that futility has commenced. The next three obstacles in sequence include lack of communication among decision makers, no agreement on a course of care, and failure to implement a timely plan of care.

**Implications:** The findings highlight the importance of determining treatment futility as an initial step in the successful delivery of palliative and end-of-life care to residents in long-term care followed by the need for a deliberate and proactive series of actions and care planning processes.

**70. Elmira Valiyeva, Louise B Russell, Jane E Miller, Monika M Safford, “Lifestyle-related risk factors and risk of future nursing home admission,” *Archives of Internal Medicine* 166 (2006):985-990.**

**Background:** While risks of disease, hospitalization, and death attributable to lifestyle-related factors such as smoking, inactivity, and obesity have been well studied, their associations with nursing home admission are less well known. These risk factors are usually established by middle age, but nothing is known about how they relate to long-term risk of nursing home admission in this age group.

**Methods:** Cox proportional hazards regressions were used to analyze risk of nursing home admission over 2 decades of follow-up (1971-1975 to 1992) in a nationally representative, longitudinal survey of community-dwelling adults aged 45 to 74 years at baseline. Middle-aged (45-64 years at baseline) and elderly persons (aged 65-74 years at baseline) were analyzed separately: 230 (6.5%) of 3526 middle-aged respondents and 728 (24.7%) of 2936 elderly ones had 1 or more nursing home admissions. Baseline risk factors included smoking, inactivity, obesity, elevated blood pressure, elevated total cholesterol level, and diabetes mellitus, which were defined according to national guidelines.

**Results:** All lifestyle-related factors, except total cholesterol level, were associated with higher risk of nursing home admission during follow-up in one or both age groups. Risk ratios were higher in middle-aged than in elderly persons. In those aged 45 to 64 years at baseline, diabetes more than tripled the risk of nursing home admission (relative risk, 3.25; 95% confidence interval, 2.04-5.19); smoking, inactivity, and elevated systolic blood pressure had relative risks of 1.56, 1.40, and 1.35, respectively. Obesity was a risk factor for those aged 65 to 74 years at baseline, but not for the middle-aged subjects. People with two lifestyle-related



factors were at greatly increased risk, especially if one was diabetes.

Conclusions: Lifestyle factors are important contributors to the long-term risk of nursing home admission. Modifying lifestyle, especially in middle age, may reduce the risk of admission.

**71. Edward V Vandenberg, Alice Tvrdik, and Brenda K Keller, "Use of the quality improvement process in assessing end-of-life care in the nursing home," *Journal of the American Medical Directors Association* 6, no.5 (2005):334-339. (6 pages)**

Examined the process and effect of a quality improvement (QI) project on end-of-life (EOL) care in a state veterans' home. The Thomas Fitzgerald State Veterans Home in Omaha, Nebraska, performed an annual survey in 2000-2003. Questionnaires were mailed to a representative of each patient who had died in the preceding year, asking respondents about quality of care in the last three months of the resident's life. The survey return rate was 8 (38%) in 2000, 22 (73%) in 2001, and 25 (55%) in 2002. Using survey results, the interdisciplinary EOL care team used continuous QI methods to improve EOL care over the three years. Specific areas that showed improvement (which also correlated with staff perceptions) were the following: overall quality of care, spiritual care, distribution of work load, and patients' preparedness for death. Prevalence of symptoms was reduced by 22% (pain), 25% (dyspnea), and 30% (uncomfortable symptoms of dying). The intervention produced a marked improvement of involvement of clergy in spiritual care. Areas that did not improve or worsened included management of depression, agitation, anxiety, loneliness, family education and discussions. Overall, 83% of survey respondents said they would recommend the facility to another family. Results suggest that EOL care can be improved using patient representative surveys as the springboard for staff and hospice interdisciplinary team QI processes.

**72. Joshua M Wiener, "An assessment of strategies for improving quality of care in nursing homes," *Gerontologist* 43 (2003):19.**

Purpose: Despite substantial regulatory oversight, quality of care in nursing homes remains problematic. This article assesses strategies for improving quality of care in these facilities.

Design and Methods: This article reviews the research literature on eight strategies: strengthening the regulatory process, improving information systems for quality monitoring, strengthening the caregiving workforce, providing consumers with more information, strengthening consumer advocacy, increasing Medicare and Medicaid reimbursement, developing and implementing practice guidelines, and changing the culture of nursing facilities.

Results: Although individual approaches vary, several themes emerge. First, several strategies require substantially more resources and will increase costs. Second, the research literature does not provide much guidance as to the effectiveness of these options. Third, several strategies assume a degree of data sophistication on the part of nursing homes that may not exist. Fourth, regulation is likely to continue to be the main strategy of quality assurance. Finally, the political saliency of nursing home quality issues is uneven.

Implications: Quality of care in nursing homes is a major issue for which there is no simple solution.

**73. Paul Willging. "PACE can show us the way," *Nursing Homes* 55, no.9 (2006)14. (2 pages)**

The U.S. has a health care delivery and financing system for America's elderly that appears largely incompatible with their health care needs. It is a delivery system more oriented toward the acute care requirements of younger populations, and a financing system focused on facility-based care, which America's seniors would prefer to avoid. Consolidated models, such as Evercare, Social Health Maintenance Organizations (S/HMOs), and Programs of All-inclusive Care for the Elderly (PACE), have done a better job of targeting recipients and integrating funding, and their results have been more promising. But they, too, have their limitations and challenges. PACE is clearly more advanced than S/HMOs, in that by focusing on seniors eligible for both Medicare and Medicaid, it receives a single, combined capitated payment from

both programs. PACE has reduced both nursing facility and hospital utilization, with a hospital length of stay of 4.9 days, compared with the Medicare average of 7.6.

**74. Ning Wu, Susan C. Miller, Kate Lapane and Pedro Gozalo, “The problem of assessment bias when measuring the hospice effect on nursing home residents' pain. *Journal of Pain and Symptom Management* 26, no.5 (2003) 998-1009.**

This study examined the observed differential documentation of pain on nursing home (NH) resident assessments (minimum data sets [MDS]) when dying residents were and were not enrolled in hospice. We studied 9,613 NH residents who died in six states in 1999 and 2000. Documented pain was compared among three groups of residents who were categorized by their hospice exposure. At the time of their last MDS completion, residents in hospice were more likely to receive opioids for their moderate to severe pain than were non-hospice residents and residents enrolled in hospice after the last MDS assessments. However, hospice residents were twice as likely as non-hospice residents and 1.3 times as likely as residents who eventually enrolled in hospice to have pain documented. These counterintuitive findings suggest that there is differential documentation of pain on the MDS when hospice is involved in care, perhaps because of superior pain assessment by hospice.

## **APPENDIX C**

### **Palliative Care in Nursing Homes Resources and Tools**

The resources and tools in this collection are organized in the following sections:

- 1. Palliative Care Information Resources: General**
- 2. Nursing Home Information Resources: General**
- 3. Nursing Home and Palliative Care Quality Improvement Initiatives**
- 4. Staffing Palliative Care Services in Nursing Homes**
- 5. Palliative Care Educational, Training and Technical Assistance Resources and Tools**
- 6. Palliative Care in Nursing Homes: Regulatory Resources**
- 7. Cultural Competency Resources**

## 1. PALLIATIVE CARE INFORMATION RESOURCES: GENERAL

### **American Academy of Hospice and Palliative Medicine (AAHPM)**

[www.aahpm.org](http://www.aahpm.org)

Membership organization that offers palliative care resources and educational and training opportunities for clinicians—physicians and nursing professionals. Sponsors the Journal of Palliative Care, a peer-reviewed journal.

### **Center to Advance Palliative Care (CAPC)**

[www.capc.org](http://www.capc.org)

Web site provides palliative care resources and information about training.

[www.capc.org/palliative-care-across-the-continuum/long-term/index\\_html#12](http://www.capc.org/palliative-care-across-the-continuum/long-term/index_html#12)

Area on CAPC Web site dedicated to resources for long-term care.

### **Education in Palliative and End-of-Life Care (EPEC)**

[www.epec.net/EPEC/Webpages/index.cfm](http://www.epec.net/EPEC/Webpages/index.cfm)

A comprehensive curriculum on essential clinical competencies in palliative care, targeted for physicians. It is delivered in train-the-trainer or online formats.

### **End-of-Life Nursing Education Consortium (ELNEC)**

[www.aacn.nche.edu/elnec](http://www.aacn.nche.edu/elnec)

[www.aacn.nche.edu/elnec/curriculum.htm](http://www.aacn.nche.edu/elnec/curriculum.htm)

A national nursing curriculum delivered in a two-day train-the-trainer conference.

### **End-of Life/Palliative Educational Resource Center (EPERC)**

<http://www.eperc.mcw.edu>

A comprehensive collection of educational resources and other information for clinicians engaged in palliative care—includes peer-reviewed educational materials.

### **Hospice and Palliative Nurses Association (HPNA)**

[www.hpna.org](http://www.hpna.org)

Leading professional palliative care membership organization for nurses at all levels (nursing assistants, LPN/LVNs, RNs and APNs) providing palliative care in all clinical settings. The association provides educational materials, including core curricula, teleconferences, annual congress, journals, newsletters and positions statements.

### **National Consensus Project (NCP) Report**

[www.nationalconsensusproject.org](http://www.nationalconsensusproject.org)

The NCP guidelines describe core precepts and structures of clinical palliative care programs divided into eight domains of care.

### **National Hospice and Palliative Care Organization (NHPCO)**

[www.nhpco.org/templates/1/homepage.cfm](http://www.nhpco.org/templates/1/homepage.cfm)

NHPCO is dedicated to promoting and maintaining quality care for terminally ill persons and their families, and to making hospice an integral part of the U.S. health care system.

### **National Quality Forum (NQF) Framework and Preferred Practices for Quality Palliative Care**

[www.nationalconsensusproject.org/NQF\\_Framework.asp](http://www.nationalconsensusproject.org/NQF_Framework.asp)

Based on the NCP guidelines, this document describes 38 preferred practices for Quality Palliative Care (see Appendix A for listing and Table 1. for examples of introducing these practices in the nursing home setting).

## **2. NURSING HOME RESOURCES: GENERAL**

### **American Association of Homes and Services for the Aging (AAHSA)**

[www.aahsa.org](http://www.aahsa.org)

A national nonprofit organization representing 5,000 nonprofit nursing homes, retirement communities, assisted living residences and senior housing facilities for the elderly.

### **American Health Care Association (AHCA)**

[www.ahca.org](http://www.ahca.org)

Advocates for quality in long-term care, the AHCA represents more than 10,000 nonprofit and for-profit providers dedicated to continuous improvement in the delivery of professional and compassionate care for frail, elderly and disabled citizens who live in nursing facilities.

### **Alliance for Quality Nursing Home Care**

[www.aqnhc.org/index.html](http://www.aqnhc.org/index.html)

### **Association of Jewish Aging Services**

[www.ajas.org](http://www.ajas.org)

A nonprofit organization that promotes the unique role and mission of Jewish-sponsored nonprofit organizations serving the elderly.

## **3. NURSING HOME AND PALLIATIVE CARE QUALITY IMPROVEMENT INITIATIVES**

### *Nursing Home Quality Improvement Initiatives*

#### **Advancing Excellence in America's Nursing Homes Campaign**

<http://www.nhqualitycampaign.org>

Advancing Excellence is a coalition-based, two-year campaign that was launched in September 2006. The campaign is reinvigorating efforts to improve the quality of care and quality of life for those living or recuperating in America's nursing homes. The campaign's coalition includes long-term care providers, caregivers, medical and quality improvement experts, government agencies, consumers and others. The campaign is building on the other quality initiatives, including Quality First, the Nursing Home Quality Initiative (NHQI), the culture change movement, and others.

**Brown University Nursing Home Care Research**

[www.chcr.brown.edu/eolcareframeset.htm](http://www.chcr.brown.edu/eolcareframeset.htm)  
[www.chcr.brown.edu/nhcareframeset.htm](http://www.chcr.brown.edu/nhcareframeset.htm)

The goal of this research group is to conduct policy-relevant studies to study to quality of nursing home care through examination of resident outcomes, processes of care, nursing home management, economic efficiency, state policies and nursing home markets.

**MedQIC Medicare Quality Improvement Community**

[www.nhqualitycampaign.org](http://www.nhqualitycampaign.org)

MedQIC supports Quality Improvement Organizations and providers in finding, Using and sharing quality improvement resources.

**National Citizens Coalition for Nursing Home Reform (NCCNHR)**

[www.nccnhr.org/default.cfm](http://www.nccnhr.org/default.cfm)

National Commission for Quality Long-Term Care  
[www.qualitylongtermcarecommission.org/index.html](http://www.qualitylongtermcarecommission.org/index.html)

Brings together government and academic leaders, consumer advocates and experts from the field, a commission working for solutions to issues in the long-term care setting.

*Culture Change Initiatives*

**“Almost Home”**

[www.almosthomedoc.org/changing](http://www.almosthomedoc.org/changing)

Web site describing the culture change movement.

**Commonwealth Fund**

[www.cmwf.org/topics/topics.htm?attrib\\_id=11989](http://www.cmwf.org/topics/topics.htm?attrib_id=11989)

Web site provides access to publications describing culture change initiatives.

**The Role of the Long-Term Care Ombudsman in Culture Change**

[www.ltombudsman.org/uploads/CultureChangeMay01.pdf](http://www.ltombudsman.org/uploads/CultureChangeMay01.pdf)

*See Appendix D for descriptions of four culture change initiatives:*

**Eden Alternative**

[www.edenalternative.com](http://www.edenalternative.com)

**Green House Project**

[www.ncbcapitalimpact.org/default.aspx?id=148](http://www.ncbcapitalimpact.org/default.aspx?id=148)

**Pioneer Network**

[www.pioneernetwork.net](http://www.pioneernetwork.net)

**Wellspring**

[www.wellspringis.org](http://www.wellspringis.org)

## *Palliative Care Quality Improvement Initiatives*

### **Improving Care Transitions**

[www.cmwf.org/spotlights/spotlights\\_show.htm?doc\\_id=430025](http://www.cmwf.org/spotlights/spotlights_show.htm?doc_id=430025)

Description of care transitions model, developed by Eric Coleman, M.D., that measures performance and care transfers.

## **4. STAFFING PALLIATIVE CARE SERVICES IN NURSING HOMES**

### *Nursing Home/Hospice Partnerships*

#### **Brown University**

[www.chcr.brown.edu/nhhsp](http://www.chcr.brown.edu/nhhsp)

### *Workforce Issues*

#### **Better Jobs for Better Care**

[www.bjbc.org](http://www.bjbc.org)

Better Jobs for Better Care is a four-year \$15.5 million research and demonstration program, funded by the Robert Wood Johnson Foundation and The Atlantic Philanthropies. The program seeks to achieve changes in long-term care policy and practice that help to reduce high vacancy and turnover rates among direct care staff across the spectrum of long-term care settings and contribute to improved workforce quality.

## **5. PALLIATIVE CARE EDUCATIONAL, TRAINING AND TECHNICAL ASSISTANCE RESOURCES AND TOOLS**

### *Educational Resources and Training Tools*

#### **American Medical Directors Association**

[www.amda.com/tools/index.cfm](http://www.amda.com/tools/index.cfm)

An extensive selection of educational, informational and problem-solving tools for practitioners and Medical Directors in long-term care.

#### **Comprehensive listing of training seminars geared to helping health care professionals develop palliative care programs**

[www.aahpm.org/about/careerdevelopment.html](http://www.aahpm.org/about/careerdevelopment.html)

#### **End-of-Life Nursing Education Consortium (ELNEC): Geriatric**

[www.aacn.nche.edu/elnec](http://www.aacn.nche.edu/elnec)

This course is designed for licensed nursing staff who work in long-term care facilities, nursing homes and hospices that serve nursing homes or other long-term care facilities. It also includes content for certified nursing assistants working in long-term care.

#### **The John A. Hartford Foundation Institute for Geriatric Nursing**

[www.hartfordign.org/resources/education/bsnPartners.html](http://www.hartfordign.org/resources/education/bsnPartners.html)



Fully scripted PowerPoint teaching slides on best nursing practices in care for older adults. Curriculum includes 20 topics.

### **IHI Training Modules**

[www.ihl.org/ihl/programs](http://www.ihl.org/ihl/programs)

IHI offers a variety of training programs designed to help health care providers to develop skills to lead improvement initiatives. Conferences, seminars and audio and Web programs are offered by category or topic.

### **Improving Nursing Home Care for the Dying: A Training Manual for Nursing Home Staff**

[www.springerpub.com/prod.aspx?prod\\_id=19255](http://www.springerpub.com/prod.aspx?prod_id=19255)

Authors: Martha Henderson, M.S.N., Dr. Min., Laura Hanson, M.P.H., M.D. and Kimberly Reynolds, M.P.A.

Eight sessions that include case studies, assessment tools, instructional guidelines and practical exercises.

### **Nurses Improving Care for Health System Elders (NICHE)**

[www.nicheprogram.org/programs/niche/resources.html](http://www.nicheprogram.org/programs/niche/resources.html)

The NICHE Program provides nursing resources and Web links for best practices in geriatric nursing care.

### **Nursing Assistant End-of-Life Care Computerized Education Project**

[www.hpna.org/Publications\\_NA\\_CEM.aspx](http://www.hpna.org/Publications_NA_CEM.aspx)

Comprehensive curriculum in CD-ROM format designed to enhance end-of-life skills of nursing assistants working in long-term care facilities. Includes vide clips, links to extensive glossary, quizzes and other information.

### **Teaching and Learning to Care: Training for Caregivers in Long Term Care**

[www.nursing.upenn.edu/centers/hcgne/gero\\_tips/TLC/default.htm](http://www.nursing.upenn.edu/centers/hcgne/gero_tips/TLC/default.htm)

Ten training modules from the University of Pennsylvania; module #6 addresses palliative care.

### **Wellspring Leadership Training Module**

[www.wellspringis.org/modules.html](http://www.wellspringis.org/modules.html)

Used to introduce projects to the Wellspring alliance.

### *Palliative Care and End-of-Life Tools*

#### **Brown University TIME Toolkit**

[www.chcr.brown.edu/pcoc/toolkit.htm](http://www.chcr.brown.edu/pcoc/toolkit.htm)

Toolkit of instruments to measure end-of-life care.

#### **Medical Orders for Life-Sustaining Treatment (MOLST)**

[www.compassionandsupport.org/molst/program.htm](http://www.compassionandsupport.org/molst/program.htm)

The MOLST program is designed to improve the quality of care people receive at the end of life by translating patient/resident goals and preferences into medical orders.

### **Physician Orders for Life-Sustaining Treatment Paradigm (POLST)**

[www.ohsu.edu/ethics/polst](http://www.ohsu.edu/ethics/polst)

POLST paradigm forms are available in many states. The form is designed to help health care professionals honor the end-of-life treatment desires of their patients. The form has physician orders that follow patient wishes and treatment intentions, and enhances the appropriateness and quality of patient care.

### **Promoting Excellence in End-of-Life Care**

[www.promotingexcellence.org/i4a/pages/index.cfm?pageid=3276](http://www.promotingexcellence.org/i4a/pages/index.cfm?pageid=3276)

This Web site offers palliative care tools in these categories: clinical care; educational; organizational; and evaluation.

### **University of Pennsylvania School of Nursing and Genesis Elder Care “Palliative Care in Nursing Home Project”**

[www.mywhatever.com/cifwriter/content/41/pe193.html](http://www.mywhatever.com/cifwriter/content/41/pe193.html)

This project developed several tools available for nursing home use.

## *Quality Improvement Tools*

### **Quality First Initiative**

[www.qualityfirstnursinghomes.com](http://www.qualityfirstnursinghomes.com)

Quality initiative from the American Health Care Association (AHCA).

### **Institute for Health Care Improvement**

[www.ihc.org/Products/ProductDetail.aspx?Product=188](http://www.ihc.org/Products/ProductDetail.aspx?Product=188)

10 Powerful Ideas for Improving Patient Care: Book 3 includes ideas to redesign the discharge process to eliminate problems at critical transition points and handoffs.

## **6. PALLIATIVE CARE IN NURSING HOMES: REGULATORY RESOURCES**

### **CMS**

[www.cms.hhs.gov](http://www.cms.hhs.gov)

[www.cms.hhs.gov/center/snf.asp](http://www.cms.hhs.gov/center/snf.asp)

[www.cms.hhs.gov/center/hospice.asp](http://www.cms.hhs.gov/center/hospice.asp)

Web sites containing information on the Medicare and Medicaid RUG (Resource Utilization) payment groups

## 7. CULTURAL COMPETENCY RESOURCES

### **Commonwealth Fund**

[www.commonwealthfund.org/usr\\_doc/Wu\\_takingcultcomptheoryaction\\_964.pdf](http://www.commonwealthfund.org/usr_doc/Wu_takingcultcomptheoryaction_964.pdf)

Taking cultural competency from theory to action, a project of the Commonwealth Fund, profiles several health care organizations that are effectively providing culturally competent care.

### **Latino Outreach Guide**

[www.nhpco.org/files/public/communications/outreach/Latino\\_Outreach\\_Guide.pdf](http://www.nhpco.org/files/public/communications/outreach/Latino_Outreach_Guide.pdf)

Produced by Caring Connections, an initiative of the National Hospice and Palliative Care Organization (NHPCO), this guide provides facts and resources for end-of-life and long-term care issues for Latinos. NHPCO will release a similar outreach guide for Asian communities by the end of 2007.

### **The John A. Hartford Foundation Institute for Geriatric Nursing- Best Practices in Care for Older Adults**

[www.hartfordign.org/resources/education/bsnPartners.html](http://www.hartfordign.org/resources/education/bsnPartners.html)

The second topic in this series of 20 featuring best practices nursing care for older adults is a PowerPoint presentation on Cross-cultural Influences on Older Adults.

### **Physicians for Human Rights**

[www.phrusa.org/racial\\_disparities/pdf/toolkit.pdf](http://www.phrusa.org/racial_disparities/pdf/toolkit.pdf)

Physicians for Human Rights developed a toolkit to address racial and ethnic disparities in health care.

## APPENDIX D

### Nursing Home Change Efforts

The culture change concept is practiced in different ways across the country (and in both for-profit and nonprofit enterprises), but all variations offer a glimpse to a positive future for nursing home residents. Four resident-centered initiatives are described below.

#### The Eden Alternative Philosophy

The Eden Alternative is an early model of culture change, and an innovative philosophy of long-term care. The foundations of the philosophy are based on the belief that loneliness, helplessness and boredom account for most of the suffering experienced in nursing homes today. The Eden Alternative Philosophy aims to improve the nursing home experience with a home-like atmosphere, including plants, animals and on-site day care for children. Eden homes strive to become residences where people can continue to live and learn rather than warehousing institutions for the frail and elderly.

Positive results of the philosophy include these findings from participating homes:

- 60 percent decrease in behavioral incidents;
- 57 percent decrease in Stage I & II pressure sores;
- 25 percent decrease in bedfast residents;
- 18 percent decrease in restraints;
- 48 percent decrease in staff absenteeism; and
- 11 percent decrease in employee injuries.<sup>1</sup>

There are about 240 homes nationwide that have adopted the Eden Alternative approach.

#### The Green House® Concept

The Green House Concept, conceived by William Thomas, M.D. (founder of the Eden Alternative), in Tupelo, Mississippi, is rooted in the tradition of the Eden Alternative. Founded on the idea that nursing home physical and social environments should be “warm, smart and green,” Green Houses seek to “deinstitutionalize” nursing home care with group homes. The first Green Houses were built in 2003 on the campus of Mississippi Methodist Senior Services in Tupelo. Each Green House has seven to 10 “elders” (a preferred term to residents, as it connotes respect for years and experience—a group size proven to reduce depression and anxiety, increase sociability and improve mobility and independence. Residents have private rooms and bring their own furnishings and decorations. Houses feature large living rooms, fully equipped kitchens, screened-in porches and dining rooms with a single, communal table. Although fully equipped with safety features and necessary medical technology, there are few “medical signposts.”

Visitors must ring door bells before entering the homes.<sup>2</sup>

In addition to changing the physical environment of nursing homes, there is also a shift in medical care focus. Physicians and nurses retain responsibility and authority, but clinical care is incorporated into elders' lives, like home care, rather than driving the daily routine. The Green House model employs a non-traditional staffing organization, where certified nursing assistants with extra training, called "Shahbazim," provide resident care. Each House is also served by a clinical support team of nurses, medical directors, social workers, physical therapists and others who visit according to schedule. The intent is to draw a clear line between care and treatment. The Houses encourage autonomy and impose no strict schedule. Residents are allowed to choose activities, mealtimes and a degree of participation in household tasks. Creators of the Green House Project maintain that financially the projects require a shifting of resources rather than an increase in resources.<sup>3</sup> With funding from the Robert Wood Johnson Foundation, the Green House Project and NCB Capital Impact are pursuing a rapid replication project on the national level, offering technical assistance and pre-development loans to organizations that want to establish a partnership with the Green House Project.

*Definition of an Elder: "An Elder is a person who is still growing, still a learner, still with potential, and whose life continues to have within it promise for, and connection to, the future. An Elder is still in pursuit of happiness, joy and pleasure, and her or his birthright to these remains intact. Moreover, an Elder is a person who deserves respect and honor and whose work is to synthesize wisdom from long life experience and formulate this into a legacy for future generations."*

— Barry Barkan

*Live Oak Institute, A Culture Change Organization*

## **The Pioneer Network**

The Pioneer Network is a culture change organization that promotes a culture of aging that is life-affirming, satisfying, humane and meaningful. The network provides information and resources on resident-centered care, and supports models where elders live in open, diverse, caring communities. Advocating and facilitating deep system change that is relationship-based and value-driven, the network hosts national conferences and regional training sessions on culture change and offers a Web site, "Pioneer Exchange," where people can share stories and post questions.<sup>4</sup>

## **The Wellspring Alliance**

The Wellspring Alliance began in 1994 as an organizational change model developed as a proactive CQI response to managed care nursing home environments. The core charter group included 11 independent nonprofit organizations in eastern Wisconsin that all embraced the idea of home-like atmospheres based on the following three concepts:

- Care decisions need to take place closest to the nursing home resident;
- A substantial knowledge base is required by all staff to enable participation

in decision making; and

- An empowered workforce increases resident and employee satisfaction and reduces staff turnover.

The Wellspring Institute provides educational modules designed to address quality indicators based on best practices established by the Agency for HealthCare Quality and Research (AHRQ), the American Medical Directors' Association (AMDA) and other professional organizations. The indicators are synthesized into eight modules for delivery of care: leadership, the older adult, elimination, nutrition, falls/restorative, well-being and palliative care.

Wellspring's practices are evidence-based, and spreading nationwide. Recent research on the homes indicated that the charter Wellspring homes have several positive outcomes—higher immunization rates, fewer bedfast residents, lower restraint use, more preventive skin care, fewer psychotropic medications, less incontinence, and fewer tube feedings—all with the same staffing levels as non-Wellspring homes.<sup>5</sup>

A Wellspring nursing home administrator interviewed in the CAPC survey made the following observation: "Wellspring's success in implementing culture change is driven by leadership. Leadership skills must be developed not only among members of the senior management team, but also among members of care resource teams, supervisory staff and front line staff."<sup>6</sup> Indeed, some researchers believe that dramatic changes in these innovative models are simply the result of charismatic leadership, and may not be replicable on a broad scale.

<sup>1</sup> [www.efmoody.com/longtern/nursingstatistics.html](http://www.efmoody.com/longtern/nursingstatistics.html)

<sup>2</sup> Rabig J, Thomas W, Kane RA, et al. "Radical Redesign of Nursing Homes: Applying the Green House Concept in Tupelo, MS." *Gerontologist* 46(4):533-39, August 2006.

<sup>3</sup> Ibid.

<sup>4</sup> [www.pioneernetwork.net](http://www.pioneernetwork.net)

<sup>5</sup> [www.wellspringis.org](http://www.wellspringis.org)

<sup>6</sup> Interview with Sr. Sarah Bertler, Administrator, St. Paul Elders, Kaukauna, WI, March 15, 2007.

## APPENDIX E

### GLOSSARY

**Advance Care Planning:** Advance care planning allows individuals to make decisions about their care if they happen to become unable to speak for themselves. Advance care planning decisions are typically based on personal values, preferences and discussions with loved ones.

**CMS:** Centers for Medicare and Medicaid Services (a division of the U.S. Department of Health and Human Services), CMS is the federal agency charged with managing the Medicare and Medicaid programs. The two health care programs—Medicare to provide access to health care for seniors aged 65 and older, and Medicaid, a program for people who can't afford to pay for medical care—were signed into law by President Lyndon B. Johnson in 1965. They were joined into one agency in 1977.

**Culture Change:** Culture Change movements focus on transitioning nursing homes from the “medical” model to “person-centered” care. Person-centered care restores control over daily living to residents of long-term care facilities and to those who work closely with them. It provides a familiar and hospitable environment, a supportive workplace and responsive, individualized care practices that focus on the needs and preferences of people, rather than those of the facility (Massachusetts Advocates for Nursing Home Reform Web site: [www.manhr.org](http://www.manhr.org)). The Culture Change movement is closely tied to nursing home Quality Improvement initiatives.

**Hospice:** A service delivery system that provides palliative care for patients who have limited life expectancy and require comprehensive biomedical, psychosocial and spiritual support as they enter the terminal stage of an illness or condition. It also supports family members coping with the complex consequences of illness, illness and disability as death nears. Hospice care further addresses the bereavement needs of the family following the death of the patients (from the National Quality Forum's report, *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*).

**Payment for Hospice Services:** Hospice care is an elected benefit covered under Medicare Part A for a beneficiary who meets all of the following conditions: the individual is eligible for Part A; the individual is certified as having a terminal prognosis of six months or less if the disease pursues its normal course; the individual receives care from a Medicare-approved program; and the individual signs a statement indicating that he or she elects the hospice benefit and waives all right to Medicare payments that are not related to the terminal illness ([www.cms.gov/MLNProducts/downloads/hospice\\_pay\\_sys\\_fs.pdf](http://www.cms.gov/MLNProducts/downloads/hospice_pay_sys_fs.pdf)).

**HIPAA:** The American Health Insurance Portability and Accountability Act of 1996, HIPAA is a set of rules to be followed by doctors, hospitals and other health care providers. HIPAA Act helps ensure that all medical records, medical billing and patient accounts meet certain consistent standards with regard to documentation, handling and privacy.



**Interdisciplinary Team:** A typical feature of palliative care delivery, the team consists of caregivers from different professional disciplines and/or services who work together to deliver palliative care services focused on care planning, optimizing quality of life and support for the individual and his or her family.

**Long-Term Care:** Long-term care covers a diverse array of health and social services provided over a sustained period of time to people of all ages with chronic conditions and functional limitations. Their needs range from minimal personal assistance with basic activities of everyday life to virtually total care. Those needs are met in a variety of care settings such as nursing homes, residential care facilities, or people's homes (Institute of Medicine in its report "Improving the Quality of Long-term Care").

**MDS:** MDS is an abbreviation for Minimum Data Set, the name given to the mandated comprehensive assessment done on every resident's functional capabilities in every long-term care facility. MDS is a tool to measure outcomes and Medicare uses it for reimbursement purposes.

**OBRA 87:** The Federal Nursing Home Reform Act from the Omnibus Budget Reconciliation Act of 1987. This was the first major revision of the federal standards for nursing home care since the 1965 creation of both Medicare and Medicaid programs. Unlike other Medicare and Medicaid providers, the OBRA legislation governs care standards and a survey and enforcement system. It created a set of national minimum standards of care and rights for people living in certified nursing facilities.

**Palliative Care:** The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making and providing opportunities for personal growth. It can be delivered concurrently with life-prolonging interventions or as the main focus of care (National Consensus Project in its report, "Clinical Practice Guidelines for Quality Palliative Care").

**Resident-Centered Care:** Resident-centered care is where nurses and other staff in nursing facilities are assigned to particular patients and have the ability to develop relationships with individual patients. Patients are treated more like family, and staff is able to become familiar with each patient and cater more to their specific needs, both emotional and medical.



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