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# Developing a Set of Indicators to Assess End-of-Life Care in Massachusetts Nursing Homes

## Final Report

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## Executive Summary

Nursing homes are often the final residence for many people. Studies have estimated that as many as 20 to 25 percent of deaths due to chronic illness in the U.S. occur in nursing homes. In recognition of the trend of increasing utilization of nursing homes as a setting for the end of life, and the opportunities and challenges for end-of-life care in nursing homes, in July 2004, Commonwealth Medicine (a division of the UMass Medical School) awarded an internal grant to the study team to develop a set of indicators that can be used to assess and evaluate the appropriateness of end-of-life care for residents of nursing homes in Massachusetts. The indicators and the results of the analysis are a basis from which future research can be conducted, and from which quality improvement programs can be initiated. This report presents the project's results.

The project was guided by an advisory group of researchers, nursing home administrators, directors of nursing, geriatricians, advocates, and policy makers. First, a comprehensive literature review was conducted to inform the project. Second, a set of indicators were developed within seven domains of end of life care: 1) structure and processes of care; 2) physical and emotional aspects of care; 3) advanced care planning; 4) ethical and legal aspects of care; 5) aggressive care near death; 6) family satisfaction; and 7) provider continuity, skill, and satisfaction. Third, the indicators were prioritized by the advisory group using a structured prioritization process in order to determine which indicators had the most relevance to assessing end-of-life care in the nursing home setting. Fourth, baseline data were collected for a small set of indicators. Data were collected from Massachusetts Medicaid claims data and a family survey.

A total of 44 indicators were developed in the seven domains. The indicators within each domain were prioritized and the results of the structured prioritization process are provided in the body of the report. Baseline data were collected for five of the indicators: death in hospital; overall hospice use; length of stay on hospice; total Medicaid resource use at the end of life; and family satisfaction.

This project sets forth a slate of indicators that can be used by nursing homes, coalitions, community groups, state agencies, and researchers to evaluate the quality of end-of-life care in nursing homes. With long histories of providing care to this vulnerable population, nursing homes can be well-positioned in the future to provide symptom management, advance care planning support, appropriate care to the imminently dying, and emotional support to staff and other residents. However, nursing homes face many challenges to providing high-quality end-of-life care. With continuing attention on the strengths of nursing homes and the needs of dying residents, improvements in the processes of care and the policy environment to support high-quality end-of-life care are possible. Moreover, the indicators presented in this report can provide the critical tools in evaluating the success of future interventions to improve the end-of-life care for nursing home residents.

## Introduction

Nursing homes are the final residence for many people. Studies have estimated that as many as 20 to 25 percent of deaths due to chronic illness in the United States occur in nursing homes (Zerzan, Stearns et al. 2000; Ersek and Wilson 2003; Wetle, Teno et al. 2004). In Massachusetts, 31.6 percent of individuals with chronic illnesses died in nursing homes in 2001, a rate higher than the nationwide rate (Brown University Center for Gerontology and Health Care Research, n.d.). As the baby-boom generation continues to age, it has been projected that as many as 40 percent of deaths will occur in a nursing home by 2040 (Ersek and Wilson 2003; Miller, Teno et al. 2004). Additionally, nursing homes are beginning to care for more frail individuals with multiple disabling conditions and complex care needs (Miller, Teno et al. 2004). Since the number of people who die in nursing homes is projected to increase and these individuals have complex care needs, the quality of end-of-life care provided in nursing homes has become an area of increasing interest.

Nursing homes have a long history of caring for dying patients and this presents unique opportunities to provide high quality end-of-life care for residents (Ersek and Wilson 2003). Nursing home staff members often build long-term relationships with patients. One of the reasons such relationships are established is because the nursing home becomes the true “home” for the individual and the staff becomes much like a family (Black and Rubinstein 2005). Such relationships can increase the opportunities for recognizing changes in residents’ status as illnesses progress and death becomes near. As identified by Reynolds and colleagues, while family members have the longest-standing personal relationships with residents, nurses are “most aware of their health status and medical treatments, and certified nursing assistants provide nearly all direct care” (Reynolds, Henderson et al. 2002). A study by Sloane and colleagues (2003) found that 71.4 percent of nursing home staff knew that death was approaching days or weeks beforehand, compared to 56.3 percent of staff in assisted living facilities. Other potential advantages that nursing homes have in providing end-of-life care include the ethnic diversity of staff and the on-site presence of a number of other professional staff, including dietitians, physical therapists, speech therapists, social workers, and others.

In addition to these opportunities, nursing homes encounter unique challenges to providing high quality end-of-life care for residents. One of the most frequently identified issues is the federal definition of nursing home quality and the associated quality indicators that were implemented in the Omnibus Budget Reconciliation Act of 1987 (OBRA) (Zerzan, Stearns et al. 2000; Reynolds, Henderson et al. 2002; Teno 2003). The quality indicators, implemented in reaction to a number of studies that identified concerns with the quality of care provided in nursing homes, have a focus on restorative care and improving residents’ functioning (Teno 2003). Unfortunately these goals often are in conflict with goals for high quality end-of-life care (Wetle, Teno et al. 2004). For example, under the system developed through OBRA, weight loss and dehydration are viewed as indicators of poor quality care, even though many individuals at the end of life may choose to forgo artificial hydration and feeding tubes and therefore will develop weight loss and dehydration, which are common symptoms at the end of life (Teno

2003). Other challenges to providing high-quality end-of-life care in nursing homes, including the lack of recognition of the futility of curative treatment, reimbursement under Medicare and Medicaid, management of pain, family dissatisfaction with care, and turnover and training of staff, are also well documented in the literature (Zerzan, Stearns et al. 2000; Reynolds, Henderson et al. 2002; Travis, Bernard et al. 2002; Ersek and Wilson 2003; Sheehan and Schirm 2003).

In recognition of the trend of increasing utilization of nursing homes as a setting for the end of life, and the opportunities and challenges for end-of-life care in nursing homes, in July 2004, Commonwealth Medicine, a division of the University of Massachusetts Medical School (UMMS), awarded an internal grant to Sarah McGee, MD, MPH of the Geriatrics Division at UMass Memorial Health Care and Darlene O'Connor, PhD of the Center for Health Policy & Research at UMMS to develop a set of indicators that can be used to assess and evaluate the appropriateness of end-of-life care for Medicaid residents of nursing homes in Massachusetts. The indicators and the results of the analysis will be a basis from which future research can be conducted, and from which quality improvement programs can be initiated. This report presents the project's results.

## Methods

### *Project Advisory Group*

An advisory group of researchers, nursing home administrators, directors of nursing, geriatricians, advocates, and policy makers was convened to advise the overall project. The advisory group met four times between August 2004 and February 2005. The advisory group provided guidance to the rest of the methods of the project and was integral in the development, refinement, and prioritization of the indicators. The advisory group members are listed in Table 1.

**Table 1: Project Advisory Group**

<b>Name</b>	<b>Affiliation</b>
Alice Bonner	Fallon Clinic and UMass Medical School
Robert Buxbaum	Massachusetts Compassionate Care Coalition and Harvard Medical School
Carlyn Lussier	Notre Dame Long-Term Care Center
Christine McCluskey	Central Massachusetts Partnership to Improve Care at the End of Life
Bernadette Meade	Fallon Clinic and Radius Hospice
Peg Metzger	Massachusetts Commission on End-of-Life Care
Ruth Palombo	Massachusetts Commission on End-of-Life Care and Massachusetts Department of Public Health
Matt Salmon	Beaumont Skilled Nursing Facility

**Table 1: Project Advisory Group (Continued)**

<b>Name</b>	<b>Affiliation</b>
Phyllis Solomon	Massachusetts Executive Office of Elder Affairs
H. Brownell Wheeler	Central Massachusetts Partnership to Improve Care at the End of Life and UMass Medical School
Sarah McGee (Principal Investigator)	UMass Medical School, Division of Geriatric
Darlene O'Connor (Co-Investigator)	UMass Medical School, Center for Health Policy & Research
Richard Beaman (Project Director)	UMass Medical School, Center for Health Policy & Research
Michael Dagilis (Research Coordinator)	UMass Medical School, Center for Health Policy & Research

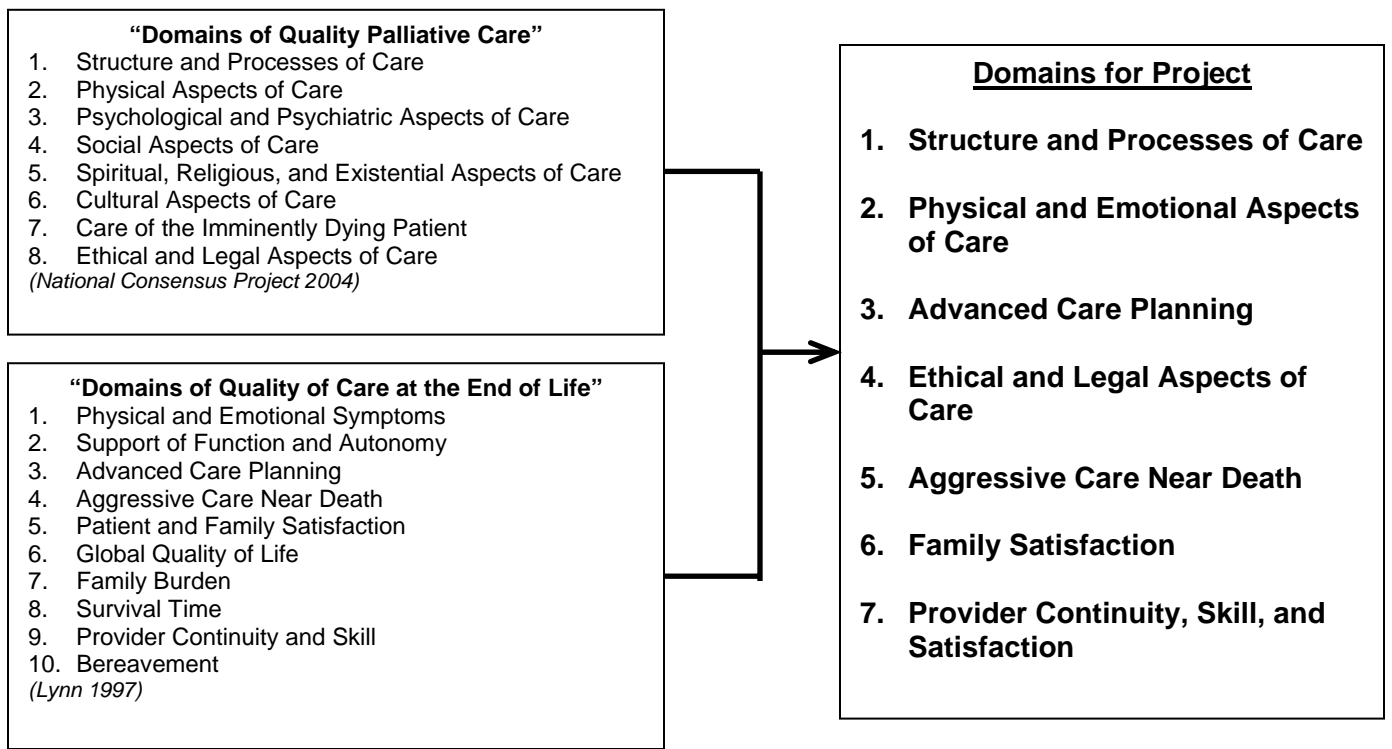
## ***Literature Review***

A comprehensive literature review was completed to inform the project. The specific goals of the literature review were to: 1) examine the current trends and issues in the field; and 2) examine current state-of-the-art techniques for measuring and documenting the provision of end-of-life care in nursing homes. A Medline search was conducted to identify relevant articles in the academic medical literature. Searches were completed using the terms “nursing homes”, “nursing facilities”, “long-term care”, “palliative care”, “hospice care”, “end-of-life care”, or combinations and variations of those terms. We located additional articles by searching other academic search engines, and collected other non-academic material via the internet. The project team then reviewed the materials to determine relevance to the project. The search resulted in 114 articles and other pieces of information that were relevant to the project.

## ***Development and Prioritization of Indicators***

To provide a framework for the development of the indicators, we reviewed existing sets of domains in the area of end-of-life care. Through this review, we identified two sets of domains that bring important but different strengths to the topic of end-of-life care in nursing homes. The first, from the National Consensus Project for Quality Palliative Care (2004), focuses on the actual practice of palliative care. The second, from Lynn (1997), focuses on the broad issues of end-of-life care. Neither of these sets of domains specifically focuses on the nursing home setting. As a result, we consolidated the two sets of domains into a single set of domains for the purposes of the project. The consolidated set of domains reflects the issues that are most frequently identified in the literature as important to the study of end-of-life care in the nursing home setting. Because the issue of end-of-life care in nursing homes is very complex, these domains do not address all of the challenging issues that exist to supporting dying residents, their families, and staff. Rather the final set of consolidated domains reflects the primary issues related to end-of-life care in nursing homes that appear to be the most well-documented and researched within the literature. The two existing sets of domains and the final set of domains that was used in this project are shown in Figure 1.

**Figure 1: Domains of End-of-Life Care**



Using information from the literature review and the experience and knowledge of the project advisory group, indicators were developed within each of the seven domains. Preference was given to indicators that had been tested previously and validated. The purpose of the indicators was to determine the state of end-of-life care for that particular domain.

The indicators within each domain that are not easily collected (i.e. are not available through claims data or other easily-obtained sources) were then prioritized by the advisory group. A structured prioritization process was utilized. The purpose of the prioritization was to determine, given limited available resources, which indicators would be most important to understanding end-of-life care in nursing homes. In other words, which of the indicators had the most relevance to assessing end-of-life care in the nursing home setting? To prioritize the indicators, each advisory committee member independently rated three factors on a scale of one to five. First, they rated the relevance (what is measured by the indicator is important to providing high quality end-of-life care in nursing homes). The second factor was actionability (a nursing home can do something to affect performance on the indicator). Finally, the third factor was improvement potential (this is an area that needs attention). Each indicator was then assigned a prioritization score by dividing the sum of the score in each of the three areas by the total possible score.

## **Data Collection and Analysis**

Because of limited funds available to this project, data were collected for only selected indicators. These indicators were selected based on the availability of data within the Massachusetts Medicaid claims system or from available surveys.

For Medicaid claims, data for individuals who died in nursing homes in Massachusetts between July 1, 2002 and June 30, 2004 were extracted from the Medicaid claims database to serve as baseline data for the selected indicators. Analysis was completed by stratifying individuals by region of residence (Boston, Central, Metrowest, Northeast, Southeast, and West), age, gender, dual-eligibility status, and race. Various statistical tests, as discussed in the results section, were used to determine significant differences between groups on the indicators. Logistic regression was used to determine the effects of different variables on the indicators.

Data from the SODIUM (Snapshot of Dying in an Urban Milieu) survey was utilized for indicators related to family satisfaction. The specific questions that were used are discussed in the results section. A random sample of 900 individuals was drawn from death certificates in Worcester, Massachusetts. The next of kin listed on the death certificate was mailed a survey. 373 of the sample returned the survey for a response rate of 45 percent. Chi-square tests were used to test for statistical significance, as is discussed more in detail in the results section.

## **Results**

Indicators were developed within each of the seven domains of end-of-life care in nursing homes:

1. Structure and Processes of Care
2. Physical and Emotional Aspects of Care
3. Advanced Care Planning
4. Ethical and Legal Aspects of Care
5. Aggressive Care Near Death
6. Family Satisfaction
7. Provider Continuity, Skill, and Satisfaction.

The purpose of the indicators is to provide a framework under which nursing homes, advocacy groups, and others can assess and evaluate the appropriateness of end-of-life care in nursing homes. The indicators should be used together; no single indicator can determine the quality of end-of-life care in nursing homes. Some indicators represent favorable conditions under which high-quality end-of-life care can occur (such as staffing ratios and the use of hospice). The indicators do not exhaustively measure all of the nuances about care at the end of life. In most cases, they do not measure personal preferences regarding care outcomes. Rather, they are designed to provide a starting point for measurement of the quality of end-of-life care. Further, they are designed to be understood easily so that they can be used by a variety of individuals interested in end-of-life care in nursing homes.

The next sections present the following information for each domain:

- Relevance of the domain;
- Indicators for the domain;
- Prioritization of the indicators (based on the priorities of the project's advisory committee); and
- Baseline data collection and analysis, if available.

## ***Domain 1: Structure and Processes of Care***

### **Relevance**

Nursing homes provide care for a diverse set of residents, including individuals recently discharged from an acute hospital for rehabilitation purposes, younger individuals with chronic or terminal illnesses, frail individuals who are cognitively impaired, and individuals who are imminently dying (Teno 2003). For a number of reasons, including cultural shifts and policy changes, nursing homes are beginning to serve residents who are more frail, have more complex illnesses, and who require more care (Wetle, Teno et al. 2004). The structure and processes that are used to provide end-of-life care to these populations serve as the foundation for all end-of-life functions. As such, nursing homes structure the provision of end-of-life care in a number of ways. Hospice and palliative care are the processes that nursing homes most frequently use to provide end-of-life care.

### Hospice

Hospice refers to a specific set of services that are provided to terminally ill individuals, including skilled pain management, personal care services, spiritual counseling, and bereavement services (Baer and Hanson 2000; Ersek and Wilson 2003). While hospice care is a broad term that can be used to describe a range of services, hospice care in the United States has generally become defined by the hospice benefit within the Medicare program. The Medicare Hospice Benefit is a specific package of services that can be elected by an individual who is determined by their physician to be in their last six months of life. When an individual elects the hospice benefit, they acknowledge that further aggressive efforts to treat their terminal illness will not be effective or appropriate. Instead, hospice provides more flexible support services focused on pain management, comfort care, and bereavement services. Hospice care in the Medicare program began in 1982 and was originally designed to be a home-based service. Congress expanded the hospice benefit through the Omnibus Budget Reconciliation Acts of 1985 and 1989 to make hospice more accessible to residents of nursing homes (Miller, Gozalo et al. 2000; Zerzan, Stearns et al. 2000; Ersek and Wilson 2003; Hayley and Sachs 2005).

Despite the high number of terminally ill residents in nursing homes, only approximately 1 percent of the nursing home population is receiving hospice benefits and only between 5 and 22 percent of nursing home residents who die are served by hospice

prior to death (Zerzan, Stearns et al. 2000; Reynolds, Henderson et al. 2002; Miller, Teno et al. 2004). Additionally, it appears that referral to hospice, if it occurs at all, often occurs too late for maximum effectiveness (Miller, Teno et al. 2004). Although few nursing home residents who die are served by hospice, hospice care has been found by some studies to improve the quality of end-of-life care in the nursing home setting (Baer and Hanson 2000; Miller Gozalo et al. 2000). According to one survey of family members of nursing home residents, the proportion of respondents who rated symptom management favorably increased from 64 percent to 90 percent after the resident began receiving hospice services (Baer and Hanson 2000). An additional study in the nursing home setting found that decedents with hospice care had better management of pain, fewer hospitalizations, and less use of feeding tubes (Miller, Gozalo et al. 2000).

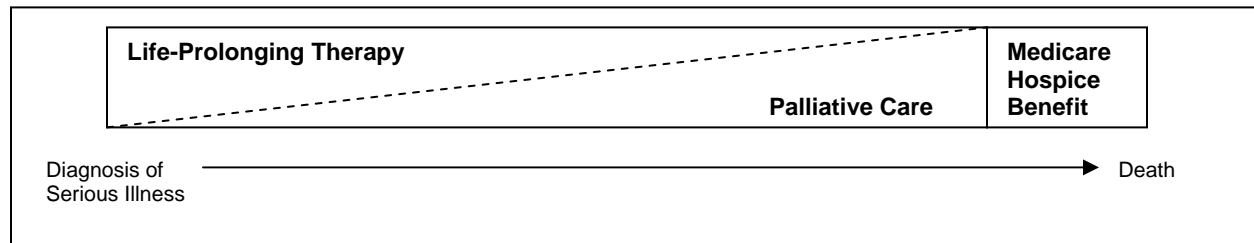
Hospice care is underutilized in the nursing home setting for several reasons. There may be a financial disincentive for nursing homes to offer hospice care to their residents. Typically, for residents who are dually-eligible for both Medicaid and Medicare and not receiving hospice services, Medicaid pays for a majority of long-term care in nursing facilities while Medicare pays for only short-term rehabilitative stays. However, financing for hospice services in nursing homes is different. For residents who are dually-eligible, Medicare begins to pay a majority of direct care costs in the nursing home when an individual elects hospice care. Medicaid pays only the room and board fees, although these fees are now paid to the hospice provider. The hospice provider then pays the nursing facility for the room and board costs. Thus the nursing facility must have a contract with a hospice provider to provide hospice services to their residents. While legislation enacted during the 1980s required state Medicaid programs to pay at least 95 percent of the nursing home room and board fee to hospice providers, the nursing facility may see a reduction in the amount it is paid for the resident who is on Medicaid and hospice (Ersek and Wilson 2003). Because higher reimbursement rates have been shown to have a positive effect on the quality of care, reduced payment from Medicaid may cause decreases in quality (Miller, Teno et al. 2004). The NIH State-of-the-Science Conference Statement on Improving End-of-Life Care (2004) recently recommended policy studies to identify barriers to and financial disincentives for effective end-of-life care in state Medicaid programs.

Another reason for the low use of hospice is that Medicare regulations require that a resident have an initial prognosis of 6 months or less to elect the hospice benefit (Ersek and Wilson 2003). Although the resident must have an initial prognosis of 6-months or less to begin hospice services, the resident can be re-certified and continue with hospice if they live beyond the 6-month timeframe. However, this is often misunderstood by family members and providers. Family and providers may believe that if an individual lives beyond six months that they would no longer be eligible for hospice. This is not unique to nursing home residents, but it does present an added disincentive to utilize hospice services, particularly for individuals with non-cancer diseases where prognostication is especially difficult (Zerzan, Stearns et al. 2000; Teno, Weitzen et al. 2001). Because nursing home residents are more likely to have chronic diseases other than cancer, the 6-month prognosis rule may be a more significant access barrier to hospice care in nursing homes (Zerzan, Stearns et al. 2000).

## Palliative Care

Whereas hospice has become known as a specific service package in the Medicare program that is provided by an outside agency under contract with a nursing home, many residents may receive palliative care services without being enrolled in hospice. Palliative care refers to care that manages symptoms, reduces discomfort, and provides social and spiritual support. According to the National Consensus Project for Quality Palliative Care (2004), 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.” This definition thus delineates the difference between palliative care and hospice care by including the words “regardless of the stage of the disease or the need for other therapies.” While hospice care under the Medicare program has the requirement of a 6-month prognosis and of forgoing life-sustaining treatments, palliative care does not have such constraints (Miller, Teno et al. 2004). Thus, through palliative care concepts, nursing homes provide many hospice-like services directly to residents who may be near the end of life. The National Consensus Project for Quality Palliative Care (2004) identified that the provision of palliative care may precede hospice care as a terminal illness progresses, as shown in Figure 2.

**Figure 2: Palliative Care’s Place in the Course of Illness**



Source: National Consensus Project for Quality Palliative Care 2004

It should be noted that in other countries, particularly Canada and the United Kingdom, because of different publicly-funded health programs that do not have rules similar to the U.S. Medicare program, hospice and palliative care have begun to be synonymous. In Canada, the term “hospice palliative care” has become more prevalent, indicating the convergence of the two concepts (Yennurajalingam, Braiteh et al. 2005).

Some nursing homes have established specialized palliative care units (or hospice units) with dedicated beds for residents who are receiving palliative care (Ersek and Wilson 2003). Others have established specialized palliative care units for specific populations, such as individuals with dementia (Hurley and Volicer 1999). In other cases, nursing homes have established palliative care consulting services, through which clinicians external to the facility provide palliative care consultation to nursing home staff (Hurley and Volicer 1999). Finally, there have been “train the trainer” models created to educate staff about palliative care methods, and some nursing homes have created palliative care teams (Ersek and Wilson 2003; Tuch, Parrish et al. 2003). Regardless of the type of program, for a palliative care initiative to be most successful, the nursing home should develop a comprehensive organizational model, including

integrating values, principles, activities, guidelines, standards, and performance measures to support the goals of palliative care (Ferris and Librach 2005).

### Physical Environment

An additional issue in the area of structure and processes of care is the extent to which a nursing home is able to provide a physical environment that meets the needs and preferences of the dying patient and their family (National Consensus Project for Quality Palliative Care 2004). Various researchers have found that the physical setting within the nursing home can have effects on cognitive functioning and physical well-being (Kayser-Jones, Schell et al. 2003). While the quality of the physical environment is important to all residents of nursing homes, it is particularly important to residents with dementia. As noted by Cohen and Day (1993), "...it has been argued that many of the behaviors attributed to dementia are, in part, a consequence of countertherapeutic settings."

One example of an effort to improve the physical environment in nursing homes is the Eden Alternative ([www.edenalt.com](http://www.edenalt.com)). Valins (1993) noted that even though current nursing homes may be far from the ideal, a vision of the future would be that nursing homes served as, "a place of contemplation and companionship, a place of light and warmth, a place of love and hope, a place of peace and yet also of activities, of music, of memories and laughter. But it would also be a place to cry, to be alone, to do as one chooses." There are other examples of hospitals that have introduced home-like atmospheres for their specialized palliative care units that may be applied to the nursing home setting (Arnold, Bailey et al. 2000).

### **Indicators**

Fourteen indicators were identified in the domain of structure and processes of care. Many of the indicators reflect conditions that allow for high-quality end-of-life care. Therefore, these indicators should be used in conjunction with indicators in other domains. Alone, improvement in these indicators will not necessarily guarantee better end-of-life care. Rather, improvement in these indicators demonstrates that there are more favorable conditions in nursing homes for high-quality end-of-life care. Also shown in the table below are potential sources of data for each of the indicators. Where "survey" is listed as a potential data source, it refers to a questionnaire or other survey instrument that would be completed by nursing home administrators, staff, family members, or other providers.

**Table 1: Indicators for Structure and Processes of Care**

<b>Indicator</b>	<b>Description</b>	<b>Possible Data Source*</b>
Hospice contracts	Percent of nursing homes with a contract with at least one hospice provider	Survey
Palliative care nursing ratio	Average number of certified palliative care nurses per resident	Survey
Mission statement addressing end-of-life care	Percent of nursing homes that have a statement contained within the nursing home's mission that addresses the home's end-of-life philosophy	Survey
Presence of affiliated non-nursing staff	Average number of other non-nursing FTEs per resident, including dietitians, social workers, therapists (PT/OT/Speech), pastoral care, activity therapist.	Survey
Specialized units	Percent of nursing homes with at least one specialized unit for end-of-life care, such as a palliative care unit or a hospice unit	Survey
Administrative staff turnover rates	Average percent of nursing home administrative staff that are new to working at the nursing home during the year.	Survey
Dedicated palliative care beds	Average percent of beds in the nursing home that are dedicated beds for palliative care residents	Survey
Palliative care physician ratio	Average number of certified palliative care physicians per resident	Survey
Evercare-affiliated nursing home	Percent of nursing homes that are affiliated and accept Evercare Medicare-managed care residents.	Survey
Presence of a sub acute care unit	Percent of nursing homes with a sub acute care unit	Survey
Payor mix	Average percent of days paid by Medicaid, Medicare, and private insurance	Survey
Religious affiliation	Percent of nursing homes affiliated with a religious denomination	Survey
Non-profit status	Percent of nursing homes that are non-profit	Medicare Compare
Staffing ratio	Average number of nursing staff hours per resident per day	Medicare Compare

\* Survey refers to a questionnaire or other survey instrument that would be completed by nursing home administrators, staff, other providers, or family members

## Prioritization of the Indicators

The project advisory committee prioritized the indicators based on the following factors:

1. **Relevance:** The extent to which the indicator is important to providing high-quality end-of-life care in nursing homes.
2. **Actionability:** The extent to which a nursing home can initiate actions that will affect performance on the indicator.

3. Improvement: The extent to which the indicator reflects an area that needs significant attention.

To prioritize the indicators, the committee ranked each indicator for these three factors on a scale of 1 to 5, where 5 is the highest possible ranking for that factor. The rankings were added together to create a sum score for each indicator. Because some committee members felt it was difficult to rank some indicators, a rank percentage was created, which was the total sum score divided by the total possible score for that indicator. A rank percentage score of 100 would indicate that each committee member ranked each factor as a “5” for that particular indicator.

The ranked list can be used by nursing homes and other groups for improvement purposes. With limited resources, nursing homes and others need to determine which areas to focus on first. Therefore, this ranked list gives those that were deemed as most important by a diverse group of practitioners, researchers, and policy makers. In other words, as shown in Table 2, the committee felt that improving the number of nursing homes with contracts with hospice would have a greater effect on end-of-life care than would attempting to alter the payor mix within the nursing home.

The following table lists the ranked indicators in the area of structure and processes of care.

**Table 2: Ranked Indicators for Structure and Processes of Care**

Rank	Indicator	Rank Score (out of 100)
1	Hospice contracts	95.0
2	Palliative care nursing ratio	85.8
3	Mission statement addressing end-of-life care	83.3
4	Presence of affiliated non-nursing staff	80.8
5	Specialized units	80.0
6	Administrative staff turnover rates	78.3
7	Dedicated palliative care beds	75.8
8	Palliative care physician ratio	72.5
9	Evercare-affiliated nursing home	62.9
10	Presence of a sub-acute care unit	57.5
11	Payor mix	53.3
12	Religious affiliation	52.5
N/R	Non-profit status	N/R
N/R	Staffing ratio	N/R

N/R=not ranked; data for these indicators are readily available from published sources.

## ***Domain 2: Physical and Emotional Aspects of Care***

### **Relevance**

There are a number of aspects of care that are important to providing high-quality end-of-life care in nursing homes. Some of the issues, as documented by the National

Consensus Project for Quality Palliative Care (2004) include physical aspects; psychological and psychiatric aspects; social aspects; spiritual, religious, and existential aspects; and cultural aspects. While researchers have investigated each of these to some extent as they relate to residents of nursing homes, the research has focused extensively on the physical and emotional symptoms that are experienced by residents at the end of life and the extent to which nursing homes are able to manage these symptoms. This section therefore focuses on the physical and emotional symptoms of end-of-life care in nursing homes. Some of the most frequently identified physical and emotional symptoms at the end of life include pain, dyspnea (difficulty breathing), and depression.

### Pain

Pain is a particularly pervasive symptom at the end of life. As such, the identification and treatment of pain has been the subject of numerous studies, although pain among elders has been less studied. According to one review, while more than 4,000 papers on pain are published each year, less than 1 percent of those focus on elders (Teno, Bird et al. n.d.).

The methods for pain identification, assessment, and treatment vary widely. As a result, there do not appear to be consistent estimates of the presence of pain or the alleviation of pain at the end of life for nursing home residents. According to two separate studies, between 8 percent and 20 percent of nursing home residents are documented as experiencing daily pain (Miller, Gozalo et al. 2000; Teno, Bird et al. n.d.). According to a review of other literature, between 33 and 83 percent of nursing home residents experience chronic pain (not necessarily daily pain), which can result in impaired mobility, depression, and reduced quality of life (Ersek and Wilson 2003; Miller, Teno et al. 2004). Reynolds et al. (2002) found that 86 percent of residents in their study experienced pain during the last three months of life. Individuals with cancer are more likely to experience pain since pain is one of cancer's most frequent symptoms (Bernabei, Gambassi et al. 1998). One review found that over 50 percent of people with cancer experience severe pain (Bonica 1990). Compounding the difficulty of estimating the prevalence of pain in nursing homes is the difficulty of pain assessment. According to a number of studies, pain evaluation is more difficult for nursing homes residents due to cognitive impairments, multiple medical problems, depression, and difficulty communicating (Teno, Bird et al. n.d.).

Because pain is prevalent for many nursing homes residents at the end of life, treatment of pain is important. Methods for treating pain can be pharmacological and non-pharmacological. According to one study of hospice and non-hospice users in nursing homes, 48.9 percent of hospice users and 24.2 percent of non-hospice users in daily pain received level 3 analgesics (Miller, Gozalo et al. 2000). According to Teno, Bird et al., 15.5 percent of nursing home residents in persistent pain in their study were receiving no analgesics at all. As a result, studies have found that often families or nursing home staff report that decedents needed more treatment for pain before death (Miller, Gozalo et al. 2000; Reynolds, Henderson et al. 2002; Teno, Bird et al. n.d.).

### Dyspnea

While rates of dyspnea, or difficulty breathing, are not well established, this appears to be a common symptom at the end of life. Studies have indicated that anywhere between 12 percent and 75 percent of nursing home residents experience dyspnea at the end of life (American Medical Association 1996; Miller, Gozalo et al. 2000; Hall, Schroder et al. 2002; Reynolds, Henderson et al. 2002). Dyspnea can be caused by chemical (oxygen and carbon dioxide levels in the blood), mechanical (airway obstruction), or emotional (increased anxiety or panic) factors (Tarzian 2000).

Dyspnea can be treated through pharmacological or non-pharmacological means (American Medical Association 1996; Hall, Schroder et al. 2002). According to a study by Hall and colleagues (2002), almost 25 percent of nursing home residents with dyspnea present prior to death received no treatment for their dyspnea. Another review of the literature confirmed that management of dyspnea appears to be very poor (Miller, Teno et al. 2004). In contrast, however, a study by Sloane and colleagues (2003) found that 50 percent of nursing home residents received treatment for shortness of breath and no residents had untreated shortness of breath. According to Miller and colleagues (2000), there is some support that hospice involvement may reduce the presence of dyspnea prior to death. Dyspnea also has the potential to lead to aggressive treatment at the end of life, including transfer to intensive care units or intubation (Keay and Schonwetter 2000). Additional issues related to aggressive care near the end of life are discussed later in this literature review.

### Depression

Depression is a prevalent emotional symptom for individuals at the end of life. According to Miller and colleagues (2000), between 13 and 15 percent of individuals in a nursing home had a “persistent mood disturbance” identified during their last assessment prior to death. Family members and staff also often report that decedents were depressed. According to one study, family members and staff said that 44 percent of residents were “very sad” or “depressed” during their last 3 months (Reynolds, Henderson et al. 2002). The rate at which depression is treated also varies. Reynolds and colleagues reported that family members and staff from 30 percent of patients said that the deceased resident needed more care for emotional and spiritual needs.

### Other Symptoms

There are a number of other symptoms that may be present at the end of life for residents in nursing homes, which often depend on the chronic illness or disease. Other common symptoms, according to various studies, include noisy breathing (Hall, Schroder et al. 2002; Sloane, Zimmerman et al. 2003), delirium (Hall, Schroder et al. 2002), fatigue (American Medical Association 1996), dehydration and hunger (McCann, Hall et al. 1994), and other functional impairments (Teno, Clarridge et al. 2004). Delirium can be a particularly challenging issue, as it is often misdiagnosed (especially as dementia) (Yennurajalingam, Braiteh et al. 2005). Agitated delirium can also be misinterpreted as an expression of pain, even if pain has been managed effectively (Yennurajalingam, Braiteh et al. 2005). Additionally, it appears that residents often have

combinations of various symptoms; one study found that 53 percent of residents had three or more of the following symptoms present in the last 48 hours of life: dyspnea, pain, noisy breathing, delirium, dysphagia, fever, or myoclonus (Hall, Schroder et al. 2002).

## Indicators

Nine indicators were identified for the domain of physical and emotional aspects of care. As can be seen in Table 3, the indicators in this domain are related to the alleviation of common symptoms at the end of life. Many of the symptoms identified in the indicators are common at the end of life. Nursing homes should focus on the alleviation of these symptoms for their dying residents.

**Table 3: Indicators for Physical and Emotional Aspects of Care**

<b>Indicator</b>	<b>Description</b>	<b>Possible Data Sources</b>
Identification of pain	Percentage of patients who died and were reported/documentated to be in pain prior to death	Chart Review or MDS
Management of pain	Percentage of patients who died and were reported/documentated to be in pain and who received pharmacological or nonpharmacological treatment	Chart Review
Reduction of pain	Percent of patients who died and underwent pain reduction processes and pain was reduced, preferably to a level acceptable to the resident	Chart Review
Psychological and social support	Percent of residents who died with psychological or social support provided by the nursing home and reported/documentated in the resident's medical record	Chart Review
Dyspnea treatment and reduction	Percent of residents who died and were reported/documentated to have dyspnea and attempts were made to minimize dyspnea	Chart Review
Presence of terminal delirium	Percent of residents who died with a diagnosis of terminal delirium documented in the medical record	Chart Review
Need for mouth care and appropriate treatment	Percent of residents who died who needed mouth care and received appropriate mouth care treatment	Chart Review
Presence of anxiety	Percent of residents who died with a diagnosis of anxiety documented in the medical record	Chart Review
Presence of agitation	Percent of residents who died with a diagnosis of agitation documented in the medical record	Chart Review

## Prioritization of the Indicators

All of the indicators in this area were ranked very highly by the committee. All but one indicator in this domain received a rank score over 90. Therefore, although Table 4 presents the rank order of these indicators, all the indicators in this domain should be viewed as critical to providing high quality end-of-life care.

**Table 4: Ranked Indicators for Physical and Emotional Aspects**

Rank	Indicator	Rank Score (out of 100)
1	Reduction of pain	97.8
2	Need for mouth care and appropriate treatment	96.2
3	Dyspnea treatment and reduction	95.6
4	Presence of anxiety	94.4
5	Presence of agitation	94.4
6	Psychological and social support	94.3
7	Management of pain	93.3
8	Presence of terminal delirium	90.0
9	Identification of pain	88.6

### ***Domain 3: Advanced Care Planning***

#### **Relevance**

Advanced care planning is important to nursing home residents because of the high likelihood of serious illness (Gillick, Berkman et al. 1999). Advanced care planning, such as written advanced directives or living wills<sup>1</sup>, can assure that a resident's wishes about life sustaining treatment and other goals of care are known by various medical providers (Levin, Wenger et al. 1999). Early advanced planning can also allow residents to guide their care before a potential inability to make decisions (Teno, Branco et al. 1997). Written advanced directives, such as do not resuscitate orders (DNR) or do not hospitalize (DNH) orders, have been the primary form of advanced care planning in the nursing home setting (Teno, Branco et al. 1997; Levin, Wenger et al. 1999). Recent studies have found, however, that written advanced directives may not improve care at the end of life. As an alternative, some have proposed that advanced care planning be more comprehensive, possibly including a set of structured discussions, and occur at targeted transition points during the course of illness for nursing home residents (Happ, Capezuti et al. 2002; Travis, Bernard et al. 2002).

#### *Written Advanced Directives*

Written advanced directives include living wills, powers of attorney, do not resuscitate orders, do not hospitalize orders, or orders to forgo artificial nutrition or hydration. The purpose of such written orders is for a nursing home resident to make clear his or her wishes prior to "a possible future period of decisional incapacity" (Teno, Branco et al. 1997). The Patient Self-Determination Act (PSDA), which was implemented in 1991, required that all health care institutions, including nursing homes, notify patients of their rights to participate in medical decision making and to complete written advanced directives (Teno, Branco et al. 1997). According to one study, the proportion of nursing home residents with a written advanced directive rose from 4.7 percent before the PSDA to 34.7 percent in 2003 (Gillick 2003). A majority of the advanced directives fall into two categories: health care proxy and/or a DNR order (Gillick 2003). In general, it

<sup>1</sup> Living wills are not legally recognized in all states, including Massachusetts.

appears that a high percentage of nursing home residents have established DNR orders and fewer residents have identified a health care proxy (someone to serve as their surrogate in the event of inability to make decisions) (Gillick 2003).

A number of studies have identified that written advanced directives can be inadequate. First, in terms of the presence of a health care proxy, studies have found “poor concordance between the views of patients and the understanding of those views by surrogate decision makers” (Gillick 2003). One potential reason for this lack of understanding by surrogate decision makers may be a lack of communication among residents, family members, and nursing home staff and physicians. Family members often find it difficult to talk about end-of-life issues and limiting care for their loved ones (Travis, Bernard et al. 2002). In a review of existing studies, Levin and colleagues (1999) found that only 12 percent of nursing home residents who were interviewed said that they had discussed their life-sustaining wishes with their healthcare provider and 31 percent said that they discussed such issues with a family member. Further discordance between the views of residents and their surrogates can occur for residents who are cognitively impaired; one pilot study on hospitalization of cognitively impaired nursing home residents concluded that “there is considerable disagreement between family representatives of cognitively impaired nursing home residents and physicians on the goals of hospital care” (Katz, Walke et al. 2001).

### *Beyond Written Advanced Directives*

The literature identifies various opportunities for expanding the role of advanced care planning beyond simple written advanced directives. In general, various articles have recommended a series of discussions with nursing home residents and their surrogates to determine individualized goals of care and discussions of residents’ preferences under a range of medical scenarios (Gillick, Berkman et al. 1999; Happ, Capezuti et al. 2002; Henderson, Hanson et al. 2003). Additionally, Happ and colleagues (2002) identified that advanced care planning should include discussions about weight loss, pain management, and other comfort care measures that the resident may desire. They also identified that there are “transition points,” such as admission, regular advanced care planning reviews, acute illness events, or decline toward death, that provide opportunities to review and update advanced care plans (Happ, Capezuti et al. 2002). The plans that result from such discussions should “incorporate patients’ goals of care, provide for patient refusal of specific treatments, allow for physician discretion, reconcile requests for specific treatments with care goals, and be readily interpretable” (Berger 2003).

Another option for advanced care planning has been operating in Oregon under the Physician Orders for Life-Sustaining Treatment (POLST) Program. The main centerpiece of this program is a medical order form that “converts patient and surrogate preferences for a variety of life-sustaining treatments into medical orders” (Hickman, Tolle et al. 2004). The POLST form includes information about preferences for resuscitation as well as the use of comfort measures, additional interventions, full treatment, use of feeding tubes, and other information. Such forms can allow

preferences for care to be converted into medical orders that can then follow patients to other settings, such as the hospital.

### Indicators

Five indicators were identified for the domain of advanced care planning. The indicators reflect the extent to which residents of nursing homes have made their end-of-life wishes known to various people. Further, communication is emphasized in the indicators through the use of advanced care planning meetings and the development of interdisciplinary teams for end-of-life planning activities.

**Table 5: Indicators for Advanced Care Planning**

Indicator	Description	Possible Data Source
Presence of comprehensive advanced care planning	Percent of residents with evidence in their chart that comprehensive advanced care planning issues were discussed during initial care plan development or through an interdisciplinary meeting after admission to a nursing home	Chart Review
Presence of interdisciplinary team for advanced care planning	Percent of residents with an identified interdisciplinary team that works with the patient and the family to plan for end-of-life care	Chart Review or Survey
Documentation of resuscitation preference	Percent of residents with evidence in their chart that a decision regarding resuscitation has been made.	Chart Review
Documentation of hospitalization preference	Percent of residents with evidence in their chart that a decision regarding hospitalization has been made	Chart Review
Health care proxy	Percent of deceased residents with a written health care proxy AND presence of a copy of the proxy in the client record.	Chart Review

### Prioritization of the Indicators

The presence of an interdisciplinary team for end-of-life planning was the highest ranked indicator in this domain. Closely related to this indicator are the actual meetings that should occur for advanced care planning with this team, which was ranked number two. The full ranked list is presented in Table 6.

**Table 6: Ranked Indicators for Physical and Emotional Aspects**

Rank	Indicator	Rank Score (out of 100)
1	Presence of interdisciplinary team for advanced care planning	92.4
2	Presence of comprehensive advanced care planning	91.4
3	Documentation of hospitalization preference	90.5
4	Documentation of resuscitation preference	88.9
5	Health care proxy	87.6

## ***Domain 4: Ethical and Legal Aspects of Care***

### **Relevance**

There are a number of ethical and legal issues surrounding end-of-life care in nursing homes. In some cases, legally-defensible practice of end-of-life care in nursing homes and ethical practice can be perceived to be in conflict with one another (Kapp 2003). Further, there is a high level of general anxiety about legal issues in nursing homes because of high-profile legal issues that have resulted in a more regulation-oriented environment for nursing homes (Kapp 2003). In general, the three primary areas of legal and ethical issues are:

- Legal issues raised by the Nursing Home Reform Act;
- Withholding or withdrawing life-sustaining treatments; and
- Adherence to advanced directives and advanced care plans.

### **Legal Issues Raised by the Nursing Home Reform Act**

Due to various legal decisions stemming from high-profile cases concerning the quality of nursing home care, regulations and public policies have been instituted at the state and federal level that have created an atmosphere that has been described as “legal anxiety” in nursing homes (Kapp 2003). In particular, as noted in the introduction to this literature review, the federal Omnibus Budget Reconciliation Act of 1987 (also known as the Nursing Home Reform Act) established the primary goal of nursing homes as “to attain or maintain the highest practicable physical, mental and psychosocial well-being of each resident” (Teno 2003). This goal therefore sets forth that “quality” care is that which attains the highest possible functioning for a resident. This definition of quality can sometimes conflict with goals in end-of-life care which often may focus on helping an individual to anticipate and accept loss of function. Therefore, under the standards set by the Nursing Home Reform Act, dehydration or weight loss would be viewed as poor quality care, even though these are common symptoms at the end of life that can be managed through the use of palliative care concepts (Teno 2003). The policy has raised questions about whether care provided in nursing homes at the end of life would be legally defensible under these quality indicators. Kapp summarizes this issue succinctly:

The main provider fear is that natural developments such as loss of weight, reduced respiration, loss of consciousness, infections, and cardiac failure are often misinterpreted as indicia of poor [end-of-life] medical care given by the nursing home rather than as the usual, expected consequences of the dying process, and that the misinterpretation may lead to attempts to hold the nursing home legally responsible for these natural developments. (Kapp 2003)

Several authors, including Kapp, have suggested that many of the concerns felt by nursing home staff and administrators are often exaggerated or misplaced (Meisel, Snyder et al. 2000; Kapp 2003). Nonetheless the apprehension that is produced by these policies does affect the practice of end-of-life care in nursing homes in tangible ways. In some cases, when there is disagreement between family, staff, and physicians

regarding the best course of treatment, many nursing homes will err on the side of more aggressive treatment at the end of life to avoid what is perceived as potential legal issues arising from less aggressive treatment, even if less aggressive treatment would be clinically more appropriate (Kapp 2003).

### *Withholding or Withdrawing Life-Sustaining Treatments*

The American Medical Association has identified that life-sustaining treatment “may include, but is not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration” (Slomka 2003). The right for patients to refuse, request withdrawal, or stop using life-sustaining treatments is legal and ethical (Mueller, Hook et al. 2004). The legal and ethical challenge often occurs in situations where a nursing home resident’s wishes in regard to life-sustaining treatments are unclear. In many cases, residents of nursing homes have not discussed their preferences for life-sustaining treatments with their physicians and/or family members (Levin, Wenger et al. 1999). Levin and colleagues (1999) cite one study in which only 12 percent of residents discussed life-sustaining treatments with their provider and only 31 percent discussed these issues with a family member. As a result, a physician and/or family member can be put in a difficult position to determine whether to withhold or withdraw life-sustaining treatments. Further, the attention to legal proceedings in cases of attempts to withdraw life sustaining treatments, such as the recent case of Terri Shiavo, has brought more legal concerns to families and physicians (Holland 2005). These issues also indicate a need for further education of families and patients regarding life-prolonging treatments.

According to the Code of Medical Ethics from the American Medical Association (Section E-2.20 Withholding or Withdrawing Life-Sustaining Medical Treatment, Updated 1996), if a patient is incompetent to make decisions, a surrogate decision maker should be identified and the physician should provide all relevant information to the surrogate for a decision to be made. The following discussion from the Code of Medical Ethics articulates the ethically-appropriate methods for determining who to consult when withholding or withdrawing life-sustaining treatments:

Though the surrogate’s decision for the incompetent patient should almost always be accepted by the physician, there are four situations that may require either institutional or judicial review and/or intervention in the decision-making process: (1) there is no available family member willing to be the patient’s surrogate decision maker; (2) there is a dispute among family members and there is no decision maker designated in an advanced directive; (3) a health care provider believes that the family’s decision is clearly not what the patient would have decided if competent; and (4) a health care provider believes that the decision is not a decision that could reasonably be judged to be in the patient’s best interests. When there are disputes among family members or between family and health care providers, the use of ethics committees specifically designed to facilitate sound decision making is recommended before resorting to the courts (American Medical Association, Updated June 1996).

Ideally, if nursing home residents have comprehensive advanced care plans, fewer ethical or legal issues will arise during decisions regarding life-sustaining treatments. Nonetheless, there will continue to be cases in which physicians and family members are required to make difficult ethical choices for nursing home residents.

*Adherence to Advanced Directives and Advanced Care Plans*

Advanced directives, which are almost always a feature of advanced care plans, are usually legally valid. In Massachusetts, court cases have established their validity (Meisel, Snyder et al. 2000). In some cases, there has been an inaccurate perception that advanced directives will guide all care for a nursing home resident, regardless of whether the resident retains decision-making capability. According to Meisel and colleagues (2000) however, “as long as a patient retains decision-making capacity, a living will or the patient’s surrogate decision maker should not be consulted about the patient’s health care decisions unless the patient expressly authorizes it.” Oral advanced directives made by a resident before becoming unable to make decisions, are also legally valid (Meisel, Snyder et al. 2000).

The National Consensus Project for Quality Palliative Care (2004) has established two separate guidelines related to ethical and legal aspects of care which impact the adherence to advanced care plans. Guideline 8.1 states, “The patient’s goals, preferences and choices are respected within the limits of applicable state and federal law, and form the basis for the plan of care.” Further, the guideline sets forth eight separate criteria that nursing homes can then follow to implement this guideline. Guideline 8.2 states, “The palliative care program is aware of and addresses the complex ethical issues arising in the care of persons with life-threatening debilitating illness.” Four criteria are then set forth to implement this guideline. Ethics committees and ethics consultants can be two avenues for resolving difficult ethical issues faced at the end of life (National Consensus Project for Quality Palliative Care 2004).

**Indicators**

Three indicators were identified in the domain of ethical and legal aspects of care, as shown in Table 7.

**Table 7: Indicators for Ethical and Legal Aspects of Care**

<b>Indicator</b>	<b>Description</b>	<b>Possible Data Source</b>
Non-adherence to do-not-resuscitate orders	Percent of residents with do-not-resuscitate orders who were resuscitated	Chart Review or Survey
Non-adherence to do-not-hospitalize orders	Percent of deceased residents with do-not-hospitalize orders who were transferred to the hospital prior to death	Chart Review or Survey
Non-adherence to other advanced directives	Percent of deceased residents with other advanced directive orders with evidence that the order was not followed at the end of life	Chart Review or Survey

## Prioritization of the Indicators

The highest ranked indicator in this domain was adherence to do-not-hospitalize orders. The other two indicators were ranked only slightly lower.

**Table 8: Ranked Indicators for Legal and Ethical Aspects of Care**

Rank	Indicator	Rank Score (out of 100)
1	Non-adherence to do-not-hospitalize orders	85.7
2	Non-adherence to do-not-resuscitate orders	84.8
2	Non-adherence to other advanced directives	84.8

## Domain 5: Aggressive Care Near Death

### Relevance

Aggressive care implies that efforts will be undertaken to prolong an individual's life. Limiting aggressive care implies that a nursing home resident or their health care proxy has chosen to forgo curative treatments in order to die more comfortably at the end of life. The preference for aggressive care at the end of life varies with each individual. Sometimes, depending on illness and the possibility for recovery, nursing facility residents or their health care proxy wish to take more aggressive measures in order to extend life. However, other residents at the end of life may choose efforts to maintain comfort and to control pain over attempts to extend life.

#### Residents' Preferences for Care

Communication between physician, nursing home staff, residents, and their surrogates is necessary in order for physicians to be aware of residents' care preferences. Unwanted aggressive care occurs more frequently when there is a poor communication between those involved directly with a resident's care. A physician's desire to prolong life and a resident's request for less aggressive care have the potential to be in conflict (Keay and Schonwetter 2000).

Various documentation procedures for communicating residents' preferences for care were described earlier in this literature review and include do-not-resuscitate orders, do-not-hospitalize orders, do-not-intubate orders, and other advanced care plans. Such procedures can help physicians, resident's surrogates, and nursing home staff to make decisions that are consistent with residents' wishes.

#### Transfer to Hospital and Location of Death

For nursing facility residents who experience acute illnesses, hospitalization can improve health, extend life, and manage pain and other symptoms. For individuals at the end of life, however, hospitalization can lead to iatrogenic illness, disruption of care plans, disorientation, stress, and unnecessary costs (Saliba, Kington et al. 2000). Other negative outcomes from hospitalization can include falls, incontinence, and delirium

(Fried, Gillick et al. 1997). Nursing facilities can often provide equally, if not more effective, end-of-life care. One review found that 36 percent of emergency department transfers and 40 percent of hospital admissions were inappropriate (as determined by a structured implicit review by physicians<sup>2</sup>), and the resident could have been appropriately cared for at a lower-intensity of care (Saliba, Kington et al. 2000). A study of short-term outcomes of individuals with pneumonia found that residents who received treatment in the nursing facility fared better than those who were transferred to the hospital for treatment, although this study was not limited to those at the end of life (Fried, Gillick et al. 1997).

As described earlier, few nursing facility residents have instituted a do-not-hospitalize advanced directive. Such directives can give guidance to nursing facility staff and physicians as to whether they should be transferred to the hospital in the last few days before death. Without DNH orders, residents are often transferred, which increases family and resident stress and dissatisfaction with the care process (Pekmezaris, Breuer et al. 2004). DNH orders do appear to reduce hospitalizations; in one study not a single person who had a DNH order was transferred to the hospital to die (Pekmezaris, Breuer et al. 2004).

### Withdrawal of Life-Sustaining Treatments

Unwanted nutritional support and hydration through intravenous or enteral routes may not only be ineffective in reducing morbidity, but may even be associated with an increase in medical complications and reduction in quality of life (McCann, Hall et al. 1994). Awareness of the patient's preference should guide the aggressiveness of care and the use of life-sustaining treatments. Artificial food and fluid administration beyond the specific requests of patients may play a minimal role in providing comfort to patients (McCann, Hall et al. 1994).

Seriously ill patients, their families, and their physicians are confronted with the responsibility of who decides the appropriate time to withdraw treatment and if that decision is aligned with the patient's wishes. With incentives to minimize health care costs, some researchers have raised concerns that decisions about the timing of the withdrawal of life-sustaining treatment will be based on economic realizations rather than patients' informed preferences (Teno 1998).

### Alternatives to Aggressive Care

When prolonging life is not the choice of the dying patient, palliative medicine, through hospice benefits and other techniques for pain and symptom control, can help provide comfort at the end of life (Keay and Schonwetter 2000). As discussed throughout this review, palliative care approaches are often preferred by elders at the end of life as well as by their family members.

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<sup>2</sup> Physicians were instructed to review each case using all available information in the resident's record to come to a determination of whether the transfer was appropriate based on whether the patient would have required resources that were typically only available in the hospital setting or if needed resources would also typically be available in the nursing facility setting.

Palliative care may be appropriate when the best treatment is one that reduces pain or causes no further deterioration of function (Katz, Walke et al. 2001). Unfortunately palliative care is often implemented too late for patients having a terminal illness. Studies have found that hospice referrals and palliative care treatment is often delayed until the week before death (Happ, Capezuti et al. 2002). Nursing home residents and their families need to feel confident that limiting aggressive care modalities will address needs for physical, psychological, emotional, and spiritual comfort associated with palliative and hospice care (Happ, Capezuti et al. 2002).

## Indicators

Seven indicators were identified for the domain of aggressive care near death. They are presented in Table 9.

**Table 9: Indicators for Aggressive Care Near Death**

Indicator	Description	Possible Data Source
Overall hospice use	Percent of all deaths in a nursing home for which the deceased was enrolled in hospice at the time of death	Claims
Length of stay on hospice	For deceased enrolled in hospice, length of time on hospice prior to death	Claims
Death in hospital	Percent of deaths that occurred in the hospital rather than the nursing home	Claims
Total Medicaid resource use at the end of life	Total per member per month costs for all Medicaid services for deceased nursing home residents for the last six months of life	Claims
Referrals to hospice	Percent of all deaths that had a prior referral to hospice	Chart Review
Preventable hospitalizations in last six months of life	Percent of all hospitalizations during the last six months of life that may be potentially preventable based on condition/reason for admit	Claims or Chart Review
Inpatient costs at the end of life	Total per member per month costs for inpatient services for deceased nursing home residents during the last six months of life	Claims

## Prioritization of the Indicators

Three of the indicators in this domain were ranked. The other four indicators were not included in the ranking because Medicaid data were made available to this project to measure those indicators. Therefore, no prioritization was needed in order to determine the relative importance of collecting data for those indicators. The ranking is presented in Table 10.

**Table 10: Ranked Indicators for Aggressive Care Near Death**

Rank	Indicator	Rank Score (out of 100)
1	Referrals to hospice	93.3
2	Preventable hospitalizations in last six months of life	90.5
3	Inpatient costs at end of life	68.6
N/R	Death in hospital	N/R
N/R	Length of stay on hospice	N/R
N/R	Overall hospice use	N/R
N/R	Total Medicaid resource use at end of life	N/R

N/R=not ranked; data for these indicators were available for this project.

## Baseline Data Collection and Analysis

Baseline data were collected for four of the indicators in the aggressive care near death domain. Data were extracted for Medicaid residents of nursing homes in Massachusetts who died during state fiscal year 2003. There were a total of 16,880 deaths during this time period for this population. The following sections present the baseline data and some analysis, as necessary.

Some limitations of the data that are presented here should be mentioned. First, administrative Medicaid claims data are limited in their scope, especially for individuals who are dually-eligible (eligible for both Medicare and Medicaid). In particular, Medicaid claims do not have any diagnosis information for dually-eligible nursing home residents. Therefore, these analyses do not take into account the diagnostic differences in dying population, which may contribute to some of the subgroup differences. Additionally, because of the central role of Medicare's hospice program to these populations, limited conclusions can be drawn without Medicare data. Nonetheless, the data that follow are a starting point to discussing end of life care in nursing homes, and the use of administrative Medicaid claims for understanding such care.

### Indicator: Death in Hospital

It is not possible in the Medicaid data to determine the exact location of death. As a proxy, data were collected to determine whether nursing home residents who died had hospital expenditures during the last month of life. Of the 16,880 total nursing home deaths, 2,430 (14.4%) had hospital use in the last month prior to death. Table 11 details the demographics and other information for this indicator.

**Table 11: Comparison of Hospital Use for Deceased Medicaid Residents of Massachusetts Nursing Homes (N=16,880)**

	Hospital Use in Last Month	No Hospital Use	Statistic	P value
<b>Total</b>	<b>2,430 (14.4%)</b>	<b>14,450 (85.6%)</b>		
Region <sup>a</sup>				
Boston	415 (17.1%)	2,018 (82.9%)	$\chi^2=101.006$	<.001
Central	247 (9.9%)	2,247 (90.1%)		
Metrowest	229 (11.9%)	1,693 (88.1%)		
Northeast	376 (12.8%)	2,555 (87.2%)		
Southeast	795 (17.3%)	3,813 (82.7%)		
West	363 (14.6%)	2,118 (85.4%)		
Age <sup>b</sup>				
30-39	8 (29.6%)	19 (70.4%)	$\chi^2=540.855$	<.001
40-49	48 (45.3%)	58 (54.7%)		
50-59	102 (39.4%)	157 (60.6%)		
60-69	217 (31.8%)	465 (68.2%)		
70-79	455 (18.6%)	1,990 (81.4%)		
80-89	996 (14.0%)	6,096 (86.0%)		
90+	597 (9.6%)	5,643 (90.4%)		
Mean age (SD)	81.51 (12.38)	86.55 (9.64)	<i>t-test</i> = 22.814	<.001
Dual eligible status				
Yes	2,208 (13.8%)	13,756 (86.2%)	$\chi^2=76.102$	<.001
No	222 (24.2%)	694 (75.8%)		
Gender				
Male	787 (17.9%)	3,610 (82.1%)	$\chi^2=59.200$	<.001
Female	1,643 (13.2%)	10,840 (86.8%)		
Race/Ethnicity				
White	1,787 (14.8%)	10,270 (85.2%)	$\chi^2=72.679$	<.001
Nonwhite	118 (26.2%)	333 (73.8%)		
Undeclared	525 (12.0%)	3,847 (88.0%)		
Hospice Use				
Yes	134 (12.3%)	952 (87.7%)	$\chi^2=3.985$	.046
No	2,296 (14.5%)	13,498 (85.5%)		

ns=not significant

<sup>a</sup>Excludes those with an unknown region.

<sup>b</sup>Excludes those under age 29.

Because the central region was of particular importance to this project, a separate analysis was completed for the central region compared to all others. As shown in Table 12, the central region had a significantly lower percentage of decedents who had hospital use prior to death (9.9% compared to 15.2%). The difference was most pronounced in those who were over age 80. The differences held true for most of the other characteristics, as shown in Table 12.

**Table 12: Regional Comparison of Hospital Use for Deceased Medicaid Residents of Massachusetts Nursing Homes (N=16,880)**

	Percent (and number) of nursing home deaths <u>with hospital use in last month of life</u>			
	Central Region (total deaths=2,494)	Outside Central Region (total deaths=14,386)	Statistic	P value
<b>Total</b>	<b>9.9% (247)</b>	<b>15.2% (2,183)</b>	<b><math>X^2=47.915</math></b>	<b>&lt;.001</b>
Age <sup>a</sup>				
30-39	16.7% (1)	33.3% (7)	$X^2=0.622$	ns
40-49	50.0% (5)	44.8% (43)	$X^2=0.099$	ns
50-59	38.2% (13)	39.6% (89)	$X^2=0.022$	ns
60-69	28.9% (28)	32.3% (189)	$X^2=0.454$	ns
70-79	15.3% (58)	19.2% (397)	$X^2=3.326$	.068
80-89	8.8% (95)	15.0% (901)	$X^2=28.941$	<.001
90+	5.2% (46)	10.3% (551)	$X^2=22.304$	<.001
Mean age (SD)	79.7 (12.97)	81.7 (12.30)	<i>t-test</i> = 2.477	.013
Dual eligible status				
Yes	9.1% (215)	14.7% (1,993)	$X^2=53.121$	<.001
No	26.2% (32)	23.9% (190)	$X^2=0.305$	ns
Gender				
Male	12.9% (91)	18.8% (696)	$X^2=14.103$	<.001
Female	8.7% (156)	13.9% (1,487)	$X^2=36.153$	<.001
Race/Ethnicity				
White	10.2% (180)	15.6% (1,607)	$X^2=35.336$	<.001
Nonwhite	27.5% (11)	26.0% (107)	$X^2=0.041$	ns
Undeclared	8.2% (686)	12.7% (469)	$X^2=11.384$	.001
Hospice Use Prior to Death				
Yes	9.8% (5)	12.5% (129)	$X^2=0.318$	ns
No	9.9% (242)	15.4% (2,054)	$X^2=49.895$	<.001

ns=not significant

<sup>a</sup>Excludes those under age 29.

Indicator: Overall hospice use

Hospice was used prior to death in 1,086 (6.4%) of the 16,880 nursing home deaths in Massachusetts. The central region had the lowest hospice use (2.0%) and the northeast area had the highest use (12.2%). Table 13 presents the full results for this indicator.

**Table 13: Comparison of Nursing Home Deaths by Hospice Use (N=16,880)**

	Hospice Use	No Hospice Use	Statistic	P value
<b>Total</b>	<b>1,086 (6.4%)</b>	<b>15,794 (93.6%)</b>		
Region <sup>a</sup>				
Boston	170 (7.0%)	2,263 (93.0%)	$\chi^2=272.355$	<.001
Central	51 (2.0%)	2,443 (98.0%)		
Metrowest	80 (4.2%)	1,842 (95.8%)		
Northeast	358 (12.2%)	2,573 (87.8%)		
Southeast	308 (6.7%)	4,300 (93.3%)		
West	118 (4.8%)	2,363 (95.2%)		
Age <sup>b</sup>				
30-39	2 (7.4%)	25 (92.6%)	$\chi^2=11.172$	.083
40-49	7 (6.6%)	99 (93.4%)		
50-59	27 (10.4%)	232 (89.6%)		
60-69	46 (6.7%)	636 (93.3%)		
70-79	166 (6.8%)	2,279 (93.2%)		
80-89	471 (6.6%)	6,621 (93.4%)		
90+	367 (5.9%)	5,873 (94.1%)		
Mean age (SD)	85.27 (10.15)	85.99 (9.80)	$t\text{-test}=2.352$	.019
Dual eligible status				
Yes	1,029 (6.4%)	14,935 (93.6%)	$\chi^2=0.072$	ns
No	57 (6.2%)	859 (93.8%)		
Gender				
Male	275 (6.3%)	4,122 (93.7%)	$\chi^2=0.318$	ns
Female	811 (6.5%)	11,672 (93.5%)		
Race/Ethnicity				
White	775 (6.4%)	11,282 (93.6%)	$\chi^2=1.052$	ns
Nonwhite	24 (5.3%)	427 (94.7%)		
Undeclared	287 (6.6%)	4,085 (93.4%)		
Hospital Use				
Yes	134 (5.5%)	2,296 (94.5%)	$\chi^2=3.985$	.046
No	952 (6.6%)	13,498 (93.4%)		

ns=not significant

<sup>a</sup>Excludes those with an unknown region.

<sup>b</sup>Excludes those under age 29.

An additional analysis was completed for the central region compared to all others. Table 14 presents the results of this indicator for the central region. As can be seen in the table, there were significant differences in the use of hospice between those in the central area and those across the rest of the state in most subgroups, except those in the younger ages (although this may be due to the small total number of deaths in those age groups).

**Table 14: Regional Comparison of Hospice Use (N=16,880)**

	Percent (and number) of deaths with <u>prior hospice use</u>		Statistic	P value
	Central Region (total deaths=2,494)	Outside Central Region (total deaths=14,386)		
<b>Total</b>	<b>2.0% (51)</b>	<b>7.2% (1,035)</b>	$\chi^2=93.634$	<.001
Age <sup>a</sup>				
30-39	0.0% (0)	9.5% (2)	$\chi^2=0.617$	ns
40-49	0.0% (0)	7.3% (7)	$\chi^2=0.781$	ns
50-59	8.8% (3)	10.7% (24)	$\chi^2=0.107$	ns
60-69	2.1% (2)	7.5% (44)	$\chi^2=3.943$	.047
70-79	3.9% (15)	7.3% (151)	$\chi^2=5.742$	.017
80-89	1.9% (20)	7.5% (451)	$\chi^2=47.049$	<.001
90+	1.3% (11)	6.6% (356)	$\chi^2=39.698$	<.001
Mean age (SD)	82.0 (10.16)	85.4 (10.13)	$t\text{-test}=2.365$	.018
Dual eligible status				
Yes	2.0% (47)	7.2% (982)	$\chi^2=92.075$	<.001
No	3.3% (4)	6.7% (53)	$\chi^2=2.090$	.148
Gender				
Male	2.4% (17)	7.0% (258)	$\chi^2=21.075$	<.001
Female	1.9% (34)	7.3% (777)	$\chi^2=72.706$	<.001
Race/Ethnicity				
White	1.8% (31)	7.2% (744)	$\chi^2=75.265$	<.001
Nonwhite	0.0% (0)	5.8% (24)	$\chi^2=2.467$	.116
Undeclared	2.9% (20)	7.2% (267)	$\chi^2=17.664$	<.001
Hospital Use Prior to Death				
Yes	2.0% (5)	5.9% (129)	$\chi^2=6.428$	.011
No	2.0% (46)	7.4% (906)	$\chi^2=89.156$	<.001

ns=not significant

<sup>a</sup>Excludes those under age 29.

Indicator: Length of Stay on Hospice

Overall, the average number of days on hospice prior to death was 12.54 days (SD=26.38) and the median was 7 days on hospice. As can be seen in Table 15, there were few significant differences among groups for those who had stays greater than seven days. The one exception was gender; men were more likely than women to be on hospice for less than seven days.

**Table 15: Comparison of Number of Days on Hospice for Hospice Users (N=1,086)**

	Hospice Use <7 days	Hospice Use >7 days	Statistic	P value
<b>Total</b>	<b>524 (48.3%)</b>	<b>562 (51.7%)</b>		
Region <sup>a</sup>			$\chi^2=0.757$	ns
Boston	82 (48.2%)	88 (51.8%)		
Central	27 (52.9%)	24 (47.1%)		
Metrowest	39 (48.8%)	41 (51.3%)		
Northeast	172 (48.0%)	186 (52.0%)		
Southeast	149 (48.4%)	159 (51.6%)		
West	54 (45.8%)	64 (54.2%)		
Age <sup>b</sup>			$\chi^2=2.426$	ns
30-39	1 (50.0%)	1 (50.0%)		
40-49	3 (42.9%)	4 (57.1%)		
50-59	12 (44.4%)	15 (55.6%)		
60-69	20 (43.5%)	26 (56.5%)		
70-79	87 (52.4%)	79 (47.6%)		
80-89	220 (46.7%)	251 (53.3%)		
90+	181 (49.3%)	186 (50.7%)		
Mean age (SD)	85.22 (9.99)	85.31 (10.31)	<i>t-test</i> = -0.142	ns
Dual eligible status			$\chi^2=0.464$	ns
Yes	499 (48.5%)	530 (51.5%)		
No	25 (43.9%)	32 (56.1%)		
Gender			$\chi^2=4.572$	.033
Male	148 (53.8%)	127 (46.2%)		
Female	376 (46.4%)	435 (53.6%)		
Race/Ethnicity			$\chi^2=1.395$	ns
White	366 (47.2%)	409 (52.8%)		
Nonwhite	11 (45.8%)	13 (54.2%)		
Undeclared	147 (51.2%)	140 (51.7%)		
Hospital Use			$\chi^2=1.839$	.175
Yes	72 (53.7%)	62 (46.3%)		
No	452 (47.5%)	500 (52.5%)		

ns=not significant

<sup>a</sup>Excludes those with an unknown region.

<sup>b</sup>Excludes those under age 29.

There were no statistically-significant differences between the central region and all others for the number of days on hospice, as shown in Table 16.

**Table 16: Regional Comparison of Number of Days on Hospice for Hospice Users (N=1,086)**

	Percent (and number) of deaths with hospice use greater than 7 days		Statistic	P value
	Central Region (total deaths with hospice=51)	Outside Central Region (total deaths with hospice=1,035)		
<b>Total</b>	<b>47.1% (24)</b>	<b>52.0% (538)</b>	<b><math>\chi^2=0.472</math></b>	<b>ns</b>
Age <sup>a</sup>				
30-39	N/A	50.0% (1)	N/A	N/A
40-49	N/A	57.1% (4)	N/A	N/A
50-59	66.7% (2)	54.2% (13)	$\chi^2=0.169$	ns
60-69	0.0% (0)	59.1% (26)	$\chi^2=2.718$	.099
70-79	33.3% (5)	49.0% (74)	$\chi^2=1.344$	ns
80-89	50.0% (10)	53.4% (241)	$\chi^2=0.091$	ns
90+	63.6% (7)	50.3% (179)	$\chi^2=0.761$	ns
Dual eligible status				
Yes	46.8% (22)	51.7% (508)	$\chi^2=0.435$	ns
No	50.0% (2)	56.6% (30)	$\chi^2=0.066$	ns
Gender				
Male	41.2% (7)	46.5% (120)	$\chi^2=0.183$	ns
Female	50.0% (17)	53.8% (418)	$\chi^2=0.189$	ns
Race/Ethnicity				
White	38.7% (12)	53.4% (397)	$\chi^2=2.563$	.109
Nonwhite	N/A	54.2% (13)	N/A	N/A
Undeclared	60.0% (12)	47.9% (128)	$\chi^2=1.083$	ns
Hospital Use Prior to Death				
Yes	20.0% (1)	47.3% (61)	$\chi^2=1.442$	ns
No	50.0% (23)	52.6% (477)	$\chi^2=0.123$	ns

ns=not significant

N/A=No deaths with prior hospice use for this group

<sup>a</sup>Excludes those under age 29.

**Indicator: Total Medicaid Resource Use at the End of Life**

In order to assess the total Medicaid resource use at the end of life, we calculated the total costs to Medicaid (including coverage of Medicare co-payments) in the last six months of life for deceased nursing home residents in Massachusetts. We then split the population by those who had expenses less than \$4,300 and those who had expenses

over \$4,300. \$4,300 was the median expenditures for the population and also likely reflects the average rate paid to nursing homes. As can be seen in Table 17, there were significant associations for almost all subgroups.

**Table 17: Comparison of Nursing Home Deaths by Medicaid Costs (N=16,880)**

	Low Medicaid Cost (<\$4,300/month)	High Medicaid Cost (>\$4,300/month)	Statistic	P value
<b>Total</b>	<b>8,415 (49.9%)</b>	<b>8,465 (50.1%)</b>		
Region <sup>a</sup>				
Boston	1,181 (48.5%)	1,252 (51.5%)	$\chi^2=15.243$	.009
Central	1,236 (49.6%)	1,258 (50.4%)		
Metrowest	1,035 (53.9%)	887 (46.1%)		
Northeast	1,439 (49.1%)	1,492 (50.9%)		
Southeast	2,301 (49.9%)	2,307 (50.1%)		
West	1,219 (49.1%)	1,262 (50.9%)		
Age <sup>b</sup>				
30-39	6 (22.2%)	21 (77.8%)	$\chi^2=150.983$	<.001
40-49	24 (22.6%)	82 (77.4%)		
50-59	65 (22.6%)	194 (74.9%)		
60-69	267 (39.1%)	415 (60.9%)		
70-79	1,241 (50.8%)	1,204 (49.2%)		
80-89	3,703 (52.2%)	3,389 (47.8%)		
90+	3,106 (49.8%)	3,134 (50.2%)		
Mean age (SD)	86.42 (8.84)	85.23 (11.42)	<i>t-test</i> =7.582	<.001
Dual eligible status				
Yes	8,055 (50.5%)	7,909 (49.5%)	$\chi^2=43.126$	<.001
No	360 (39.3%)	556 (60.7%)		
Gender				
Male	2,435 (55.4%)	1,962 (44.6%)	$\chi^2=72.647$	<.001
Female	5,980 (47.9%)	6,503 (52.1%)		
Race/Ethnicity				
White	5,808 (48.2%)	6,249 (51.8%)	$\chi^2=70.019$	<.001
Nonwhite	196 (43.5%)	255 (56.5%)		
Undeclared	2,411 (55.1%)	1,961 (50.1%)		
Hospice Use				
Yes	566 (52.1%)	520 (47.9%)	$\chi^2=2.384$	.123
No	7,849 (49.7%)	7,945 (50.3%)		
Hospital Use				
Yes	1,134 (46.7%)	1,296 (53.3%)	$\chi^2=11.520$	.001
No	7,281 (50.4%)	7,169 (49.6%)		

ns=not significant. <sup>a</sup>Excludes those with an unknown region. <sup>b</sup>Excludes those under age 29.

As shown in Table 18, there were no significant differences between the central region and those outside the central region in the percent of deceased residents with high and low Medicaid costs.

**Table 18: Regional Comparison of Nursing Home Deaths by Medicaid Costs (N=16,880)**

	Percent (and number) of deaths with high Medicaid cost (>\$4,300/month)		Statistic	P value
	Central Region (total deaths=2,494)	Outside Central Region (total deaths=14,386)		
<b>Total</b>	<b>50.4% (1,258)</b>	<b>50.1% (7,207)</b>	<b><math>\chi^2=0.100</math></b>	<b>ns</b>
Age <sup>b</sup>				
30-39	83.3% (5)	76.2% (16)	$\chi^2=0.138$	ns
40-49	80.0% (8)	77.1% (74)	$\chi^2=0.044$	ns
50-59	73.5% (25)	75.1% (169)	$\chi^2=0.039$	ns
60-69	57.7% (56)	61.4% (359)	$\chi^2=0.462$	ns
70-79	47.1% (179)	49.6% (1,025)	$\chi^2=0.823$	ns
80-89	49.5% (534)	47.5% (2,855)	$\chi^2=1.481$	ns
90+	50.5% (444)	50.2% (2,690)	$\chi^2=0.022$	ns
Dual eligible status				
Yes	50.0% (1,185)	49.5% (6,724)	$\chi^2=0.192$	ns
No	59.8% (73)	60.8% (483)	$\chi^2=0.044$	ns
Gender				
Male	42.3% (298)	45.1% (1,664)	$\chi^2=1.782$	.182
Female	53.6% (960)	51.8% (5,543)	$\chi^2=1.977$	.160
Race/Ethnicity				
White	51.5% (911)	51.9% (5,338)	$\chi^2=0.076$	ns
Nonwhite	70.0% (28)	55.2% (227)	$\chi^2=3.236$	.072
Undeclared	46.5% (319)	44.5% (1,642)	$\chi^2=0.893$	ns
Hospice Use Prior to Death				
Yes	39.2% (20)	48.3% (500)	$\chi^2=1.611$	ns
No	50.7% (1,238)	50.2% (6,707)	$\chi^2=0.160$	ns
Hospital Use Prior to Death				
Yes	56.7% (140)	53.0% (1,156)	$\chi^2=1.237$	ns
No	49.8% (1,118)	49.6% (6,051)	$\chi^2=0.022$	ns

ns=not significant

<sup>b</sup>Excludes those under age 29.

## ***Domain 6: Family Satisfaction***

### **Relevance**

Recent research has focused on family members' satisfaction with their loved one's experience of dying in a nursing home as well as the extent to which support is provided to family members of residents at the end of life. This research has focused on what family members view as a "good death," and to what extent they feel that their loved ones experienced a good death (Baer and Hanson 2000; Reynolds, Henderson et al. 2002; Teno, Clarridge et al. 2004). The perceptions of family members offer valuable information about the dying experience because family members generally remain close to their dying loved ones and often critique the quality of the care provided (Wetle, Teno et al. 2004).

Studies have shown that family members are concerned about pain and symptom management, attention to spiritual needs, the presence of family at the end of life, communication from nursing home staff, and the extent to which nursing homes promote shared decision making (Baer and Hanson 2000; Steinhauser, Christakis et al. 2000; Teno, Clarridge et al. 2004). A study by Steinhauser and colleagues (2000) found that family members ranked freedom from pain, at peace with God, and presence of family as the top three attributes for a good death. In the same study, patients and physicians also ranked these as the top three attributes, indicating fairly strong consistency in the perceptions of family members, physicians, and patients as factors that are important for a good death.

The extent to which family members are satisfied with the performance of nursing homes in these various areas appears to vary in the literature. According to one study that compared nursing homes to assisted living facilities, in some areas (including personal assistance with care, untreated pain, and treatment for shortness of breath), family members of those who died in nursing homes reported higher satisfaction than those who died in assisted living facilities (Sloane, Zimmerman et al. 2003). In other areas, however, including involving family in care and treatment decisions and some selected physician performance issues, assisted living facilities performed better than nursing homes, according to family members (Sloane, Zimmerman et al. 2003).

Two recent studies have been particularly important to understanding the perceptions of family members of deceased nursing facility residents. The first, by Teno and colleagues (2004), was a large-scale mortality follow-back survey of family members after the death of their loved one. This survey compared the perceptions of family members of those who died in nursing homes to those who died at home with and without hospice services as well as to those who died in the hospital. The results showed that family members of nursing home decedents reported higher rates of unmet needs from pain and emotional support. Families also reported that there were more concerns about whether the person who died in a nursing home was treated with respect. Unfortunately the study did not include those with hospice services in the nursing home setting.

The second important study, completed by Wetle and colleagues and released by the AARP Public Policy Institute in 2004, was a follow-up to the above survey and contained the results of in-depth qualitative interviews with family members after death. This study confirmed the earlier study, finding that the symptoms and needs of dying patients in nursing homes are “insufficiently recognized by professional caregivers with the result that opportunities for palliative intervention and advance care planning are missed” (Wetle, Teno et al. 2004).

Opportunities to improve the dying experience, and therefore family satisfaction with the process, have been identified in the literature. In particular, family members of individuals who receive hospice benefits in the nursing home appear to be more satisfied (Teno, Clarridge et al. 2004). The report by Wetle, Teno, and colleagues (2004) also identified a number of important opportunities to improve care, including:

- educating health professionals;
- training physicians in end-of-life care;
- training nursing home staff and administrators;
- informing the public about end-of-life care in nursing homes;
- developing new knowledge and improved practices through centers of excellence;
- educating families about what to expect during the dying process, and increasing the support for families of nursing home residents at the end of life; and
- developing and refining policies that support high-quality end-of-life care.

As can be seen from this list of opportunities, the satisfaction of family members with the dying experience in the nursing home is often a reflection of external policy issues, as well as internal nursing home issues, which affect the practice of care in nursing homes (Wetle, Teno et al. 2004).

## Indicators

As can be seen in the above discussion, there are a number of ways in which family satisfaction can be measured. There are qualitative options for measuring satisfaction, such as open-ended questions regarding the end-of-life care that was provided to loved ones. Alternatively, surveys can be conducted that ask a battery of questions related to different domains and issues about end-of-life care. Therefore, this project did not specifically determine what items should be asked of surviving family members. Rather, this project set forth a single broad indicator, “family satisfaction”, to represent the importance of measuring and understanding the satisfaction of those who survive beyond the death of a loved one. The exact methods and definition of “family satisfaction” would depend on the goal of any particular measurement activity. Because only one indicator was established, no ranking was necessary.

**Table 19: Indicator for Family Satisfaction**

Indicator	Description	Data Source
Family satisfaction	Percent of family members of deceased residents satisfied that the nursing home provided the desired physical comfort and emotional support to the dying person.	Survey

### Baseline Data Collection and Analysis

During 2005, the health care workgroup of the Central Massachusetts Partnership to Improve Care at the End of Life conducted a survey of family members of individuals who had recently died. The study, known as the SODIUM study (Snapshot of Dying in an Urban Milieu), was conducted under the direction of Dr. David Kaufman of St. Vincent’s Hospital.

The SODIUM study survey included family members of individuals who had died in multiple settings, including hospitals, intensive care units, home, and nursing homes. For the purposes of the present study, we analyzed the responses on selected survey questions for those who died in nursing homes (n=93) compared to those who died in all other settings (n=275). We selected questions to analyze based on their relevance to other domains of this project. Respondents were asked to rate how well each aspect of care was achieved on a four-point likert scale (always, usually, sometimes, or never). For analysis, responses of “always” and “usually” were grouped together and the other two responses were grouped. Chi-square tests were used to test statistical significance between those who died in nursing homes and those who died in other settings.

First, the survey asked whether or not the person who died had a health care proxy and/or a do-not-resuscitate order (see Domain 3: Advanced Care Planning). As shown in Table 20, a majority of individuals in nursing home and non-nursing home settings had a proxy and/or a do-not-resuscitate order. A statistically significantly higher percentage of those who died in nursing homes had a do-not-resuscitate order compared to those who died in other settings.

**Table 20: Presence of Health Care Proxy and DNR Orders in Nursing Homes Compared to Other Settings**

	Nursing Home	Other Settings	Statistic	P-value
Percent with Health Care Proxy	88.4% (76)	81.2% (203)	$\chi^2=2.337$	.126
Percent with DNR Order	88.9% (72)	75.3% (177)	$\chi^2=6.639$	.010

Table 21 presents findings from five specific questions, each of which corresponds to a domain within this project:

1. Was your loved one’s pain controlled well enough? (Domain 2)
2. Were his/her uncomfortable symptoms controlled well? (Domain 2)
3. Was your loved one’s anxiety well controlled? (Domain 2)

4. Immediately before death, were your loved one’s troublesome symptoms relieved? (Domain 5)
5. Were his/her wishes regarding end of life followed? (Domains 4 and 5)

Overall, a very high percentage of respondents responded “always” or “usually” to each of the questions in both nursing home and other settings. Although there appears to be a slightly higher percentage of family members of individuals who died in other settings who responded positively to each question, there were no statistically-significant differences.

**Table 21: Responses to Family Survey**

	Percent responding “Always” or “Usually”		Statistic	P-value
	Nursing Home	Other Settings		
Pain controlled well enough (n=313)	84.3% (70)	86.5% (199)	$\chi^2=0.241$	.624
Uncomfortable symptoms controlled well (n=309)	80.7% (67)	85.4% (193)	$\chi^2=0.994$	.319
Anxiety well controlled (n=295)	76.5% (65)	81.9% (172)	$\chi^2=1.131$	.288
Troublesome symptoms relieved immediately prior to death (n=273)	84.9% (62)	86.0% (172)	$\chi^2=0.050$	.823
Wishes were followed (n=261)	92.8% (64)	93.2% (179)	$\chi^2=0.018$	.894

### ***Domain 7: Provider Continuity, Skill, and Satisfaction***

#### **Relevance**

There are a number of provider issues that impact the provision of end-of-life care in nursing homes, including the connection and communication between nursing homes and other healthcare providers, staff shortages and turnover, staff training needs, and the support to staff following the death of a resident.

#### *Connection to Other Healthcare Providers*

In many cases, nursing homes are isolated from the larger healthcare community and even from the communities in which they are located (Ersek and Wilson 2003). Additionally, there are varying levels of physician involvement in nursing homes, and often physicians can be seen as “missing in action” for residents in nursing homes (Ersek and Wilson 2003; Miller, Teno et al. 2004; Wetle, Teno et al. 2004). This lack of connection to other healthcare providers can have significant impacts on the end-of-life care that is provided to residents. The NIH Statement on Improving End-of-Life Care noted that, “lack of flow of information across providers and settings” also was one of the continuing problems in end-of-life care (NIH 2004). A lack of communication between physicians and nursing home staff can have a negative effect on the quality of care (Ersek and Wilson 2003). Communication between the nursing home and hospitals

can be critical in order to facilitate appropriate care plans that match resident preferences when it is necessary to transfer a resident to an acute care facility.

When a resident is receiving hospice services in the nursing home, communication and collaboration between the hospice agency and nursing home staff can be problematic (Miller, Teno et al. 2004; Wetle, Teno et al. 2004). First, the financing arrangements between hospices and nursing homes can present inherent difficulties in contracting and coordinating hospice care for nursing home residents (Ersek and Wilson 2003). Additionally, differences in philosophies, approaches to care, and regulatory oversight can impact the coordination between hospice services and nursing homes (Wetle, Teno et al. 2004). Currently, nursing homes and hospices are required to have the same care plan for a resident who is receiving hospice services, but there is some evidence that the integration of clinical care remains an issue (Wetle, Teno et al. 2004).

### Staff Shortages and Turnover

Recent studies have shown that the number of certified nursing assistants (CNAs) and licensed and registered nurses in most nursing homes is below levels recommended by recent Centers for Medicare and Medicaid Services studies (Miller, Teno et al. 2004). Further, the level of nursing assistant availability appears to positively affect the quality of end-of-life care (Miller, Teno et al. 2004). Additionally, it is well understood that there is high turnover among staff, particularly direct care staff such as CNAs, in nursing homes. The reasons for the high turnover include low wages, high stress, low societal respect for such jobs, and high paperwork burdens (Ersek and Wilson 2003). The high turnover has an effect on the quality of end-of-life care for several reasons. First, the high turnover can influence the effectiveness of educational initiatives designed to increase staff's knowledge of palliative care and end-of-life care issues. This is particularly challenging for CNAs who typically have little training on end-of-life care. Second, high turnover can affect the direct care of residents because staff members develop family-like relationships with residents. Staff members who work with residents over a longer period of time will be more apt to recognize changes in health status (Reynolds, Henderson et al. 2002).

### Educational and Training Needs of Staff

The formal level of training for nursing home staff varies. For CNAs, the typical level of formal education is a high school diploma. Licensed practical nurses (LPNs) generally have formal education that takes an additional 12-24 months and limited content on end-of-life care issues. Registered nurses (RNs) have more education, but are more often in administrative and supervisory roles, rather than in direct care (Ersek and Wilson 2003). Even for nurses and nursing assistants with additional academic experience, the academic training often doesn't include training in palliative care (Miller, Teno et al. 2004). As a result of the generally low formal education of various staff, training opportunities have been an important method for improving the quality of end-of-life care in nursing homes. Opportunities for training include:

- general end-of-life issues;
- symptom management;

- communication with dying residents and their families;
- ethical considerations;
- principles of resident-centered care; and
- identification of decision-points in the dying process (Kyriacou and Nidetz 2002; Wetle, Teno et al. 2004).

There have been several successful examples of educational interventions. One model, which consisted of a curriculum of lectures and mentoring sessions for physicians, nurses, administrators, social workers, and other staff showed positive trends toward increasing palliative care access and improving the perception that an administrator should participate in palliative care decision-making for the nursing home (Kyriacou and Nidetz 2002). Staff also indicated improvements in understanding pain medications and the ability to discuss death and dying with residents and families. Staff also reported that they felt more confident in providing palliative care services following the intervention (Kyriacou and Nidetz 2002). Other programs have utilized “train the trainer” concepts, in which one key individual from a nursing home is trained and this individual then trains the other staff members. One challenge for educational initiatives, as noted earlier, is the high staff turnover that can affect the usefulness of the initiatives (Ersek and Wilson 2003).

Providing educational opportunities for physicians is also very important. Changing physician behavior can be possible if effective strategies are utilized (Keay, Alexander et al. 2003). Recommendations from the report by Wetle and colleagues (2004) indicate that some opportunities for educating physicians on end-of-life care include requiring various specialties to follow a panel of terminally-ill patients over the course of their residency training; requiring physician residents to follow individual patients as they leave the hospital and enter a nursing home; and providing general medical education funding to support training in palliative care and geriatric fellowships. A review of the literature by Keay and colleagues (2003) found that “multifaceted interventions that include audit and feedback, reminders, [and] local consensus processes...” have all been shown to be effective.

### Support Provided to Staff

Direct care workers in nursing homes interact most closely with residents. As such, direct care workers are often impacted quite significantly following the death of someone for whom they were caring (Black and Rubinstein 2005). The direct care worker’s experience in the nursing home is different than that of the direct care worker in other settings. One review of the literature in this area found that, “Because direct care workers are often repositories for intimate knowledge about a resident’s life, metaphors and themes of family life are prevalent in their discussions of work” (Black and Rubinstein 2005). For this reason, the support that is provided to staff during a resident’s dying process and after a resident dies is important and affects the level of satisfaction of the nursing home staff.

One option for providing technical support to staff during a resident’s last days is through a palliative care consultation service. Such a service is either externally based

(clinicians come from outside the nursing home) or is comprised of palliative care experts within the facility. These individuals are then available to staff to provide information, education, and training on palliative care needs of current residents (Ersek and Wilson 2003). Other training methodologies can also improve the confidence of staff to provide quality palliative care services.

Emotional support should also be provided to staff and other residents during and after the death of a resident. As one training manual for staff noted, “After a resident dies, staff members need to remember the resident, to share feelings with others, to grieve, and to get support from others” (Henderson, Hanson et al. 2003). Some ideas noted by this training manual include telling the resident good-bye, letting other staff and residents know what happened and giving them time to respond, and conducting memorial services in the nursing home. These strategies can assist not only the staff who are grieving, but also other residents who need bereavement support.

### Indicators

Five indicators were identified for the domain of provider continuity, skill, and satisfaction. They are presented in Table 22.

**Table 22: Indicators for Provider Continuity, Skill, and Satisfaction**

Indicator	Description	Data Source
Consistency of care plans	Percent of residents receiving hospice benefits where the hospice care plan is consistent with the nursing home care plan	Survey
Educational opportunities for staff	Number of educational sessions related to end-of-life care held for staff in prior 12 months per nursing home	Survey
Memorial services	Percent of nursing homes that hold regular memorial services following the death of residents	Survey
Palliative care consultation service	Percent of nursing homes with a palliative care consulting service available to staff	Chart Review
Staff turnover rates	Percent of nursing home staff that are new to working at the nursing home during the year	Survey

### Prioritization of the Indicators

The percent of nursing homes that hold memorial services for deceased residents was the highest ranked indicator in this domain. The ranking of other indicators is presented in Table 23.

**Table 23: Ranked Indicators for Provider Continuity, Skill, and Satisfaction**

Rank	Indicator	Rank Score (out of 100)
1	Memorial services	93.3
2	Educational opportunities for staff	90.5
3	Palliative care consultation service	88.6
4	Consistency of care plans	83.3
5	Staff turnover rates	76.2

## Summary and Future Use of the Indicators

There are a number of other issues related to end-of-life care in nursing homes that have not been addressed in this project. The omission of those issues should not diminish their importance to fully understanding the experiences of nursing home residents at the end of life. As noted earlier, the project's literature review was used to frame much of this project. That literature review focused primarily on the key aspects of end-of-life care that appear most frequently in the literature and appear to have been more thoroughly researched. In many cases, while other issues have not been as thoroughly researched related to persons in nursing homes, this may be an important indication that additional research in end-of-life care in nursing homes is warranted. Some of the other issues that have been identified during the course of conducting the project include the following items.

- The extent to which caregiving burden affects family members with loved ones residing in a nursing home at the end of life.
- Attention to spiritual and existential issues for residents at the end of life.
- The effectiveness of alternative treatment options for symptom management, including the use of alternative medicines.
- The impact of cultural issues and disparities in end-of-life care in nursing homes.

This is not an exhaustive list of possible areas that should be further considered to develop a complete understanding of end-of-life care in nursing homes. One of the key considerations is to understand how inherently complex and interconnected these issues are.

Nonetheless, this project has set forth a slate of indicators that can be used by nursing homes, coalitions, community groups, state agencies, and researchers to evaluate the quality of end-of-life care in nursing homes. As stated earlier, it is important that the indicators be used together; any one indicator doesn't provide a complete picture of end-of-life care in nursing homes. Because the topic is extremely complex, it is important to consider many issues together.

This report provides some data on selected indicators. These data can be used as baseline information for future monitoring of the status of end-of-life care in nursing homes. Community groups across the state can use the baseline information to plan interventions and measure the success of such interventions. In the Worcester area, the Central Massachusetts Partnership to Improve Care at the End of Life has already

conducted several training sessions with staff from local area nursing homes on end-of-life care. Perhaps such training sessions will have the effect of improving end-of-life care in those nursing homes. The indicators presented here could be used to assess such improvement.

Nursing homes are the final residence for many people, and they have a unique opportunity to provide high-quality end-of-life care to their residents. With long histories of providing care to this vulnerable population, nursing homes can be well-positioned in the future to provide symptom management, advance care planning support, appropriate care to the imminently dying, and emotional support to staff and other residents.

Nursing homes, however, as discussed in this report, currently face many challenges and obstacles to providing high-quality end-of-life care. From regulatory requirements that may be in conflict with the goals of end-of-life care, to issues of staff turnover and educational needs, there is much to be accomplished. With continuing attention on the strengths of nursing homes and the needs of dying residents, improvements in the processes of care and the policy environment to support high-quality end-of-life care are possible. Moreover, the indicators presented in this report can provide the critical tools in evaluating the success of future interventions to improve the end-of-life care for nursing home residents.

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