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I introduce this second themed issue on the subject of long-term care in Rhode Island (RI) by noting that it is again dedicated to the memory of **DR. STANLEY M. ARONSON**, an ardent and longtime champion of humane health care in general and the enlightened medical approach in particular for the care of older adults. The platform of being guest editor allows me to speak once more for the values Dr. Aronson held dear about how competent and excellent care must be based fundamentally in the unique needs, life story and preferences of the individual patient. His emphasis on respect for the person and superb medical competence were instrumental values that led to his initiating hospice care to RI (Home and Hospice Care of RI, founded in 1974), Interfaith Health Care Ministries (founded in 1975) as well as embedding interdisciplinary approaches to medical care in the Brown Program in Medicine (now The Warren Alpert Medical School of Brown University).

The papers in the March 2015 issue of RIMJ ([http://rimed.org/rimedicaljournal/2015/03/2015-14-ltc-complete.pdf](http://rimed.org/rimedicaljournal/2015/03/2015-14-ltc-complete.pdf)) provided an overview of the evolving medical landscape of long-term care in RI and offered first-hand experiences of those directly involved in providing long-term care: the medical director, the nursing home administrator and the long-term care nurse.

This issue focuses on the journey in long-term care, specifically transitions and end of life. Medical care for older adults is often marked by frequent transitions in sites of care, moves that are fraught with difficulty as physicians and other caregivers rush to move the patient from site to site, too often without adequate preparation and sufficient information to ensure that the move is accomplished well and safely.

Vognar and Mujahid describe how transitions between hospital and nursing home challenge the provision of the most effective care; they provide practical advice about how to manage transitions in a smoother and safer way. The article by Shield, Thomas and Ratchford takes the perspective of patients who have actually undergone these transitions. They focus on how patients recalled their journeys from home to hospital to nursing home for rehabilitation. They highlight how the transitions as seen from the patients’ point of view can be frightening and challenging, the patients also offer advice to physicians about how these moves could be managed better.

The final two articles discuss the role of hospice and palliative care in the long-term care institution. Miller describes how hospice and palliative care can best be utilized in this setting and how these approaches can effectively alleviate patients’ pain and suffering. Physicians are themselves sometimes the barrier to patients and their families accessing adequate relief for their conditions. Martin next addresses how physicians can talk with patients and families in “goals-of-care” conversations about end-of-life choices in a realistic and comforting way. He offers a blueprint of a clear approach to clarifying patient goals and preferences physicians can use to effectively implement these dialogues into their clinical practice.

Dr. Aronson intimately understood the inherent brevity and finality of our transient lives. His life is an example of how to enrich the limited time we have to maintain and heighten the preciousness of life itself. Older patients are at the end of long, complex and intensely unique lives. His painting featured on the cover speaks to a lengthy journey into a vast unknown. When we care for older patients, we need to respect their individuality and honor the specific experience of who each of them is. We thank Dr. Aronson for reminding us of the compassionate view of age and mortality and for helping us find a practical and informed way to care for patients in the best ways possible. In continuing the spirit and example of Stan Aronson, I sincerely hope the articles in this issue convey the message of how to better care for older adults as they approach the ends of their lives.

**Guest Editor**

Renée R. Shield, PhD, is Professor of Health Services, Policy and Practice (Clinical) at the Center for Gerontology and Healthcare Research, Brown University School of Public Health.
Healthcare Transitions of Older Adults: An Overview for the General Practitioner

LIDIA VOGNAR, MD; NADIA MUJAHID, MD

ABSTRACT
Healthcare transition refers to the care “hand-off” of a patient among providers and treatment settings. Older adults experience more frequent care transitions than younger patients due to the presence of co-morbidities, cognitive impairment, increased dependence and medication use. Hospitalization and subsequent readmission after discharge to a nursing home represents a unique care transition situation. It is estimated that as many as 60% of readmissions from nursing homes can be avoided. Poor communication between hospital and nursing home staff; delayed, inaccurate, or missing discharge summaries; lack of accurate medication reconciliation; pending test results; inappropriate follow-up; and poor education of patient and families all contribute to poor care transition quality, and increase the probability of rehospitalization. Interventions for improved care transitions are suggested. They focus on patient and family-centered care effectiveness, minimizing adverse events, and increasing timely, accurate and complete communication.

KEYWORDS: Healthcare transitions, nursing home residents, hospital readmission rates

INTRODUCTION
A healthcare transition occurs when a patient moves among providers or treatment settings coincident with a change in a patient’s condition or health care needs. These care settings include hospitals, nursing facilities [NFs], rehabilitation centers, and home.1 Effective and safe care transitions depend upon a set of actions designed to ensure the coordination and continuation of healthcare as patients transfer between locations and levels of care.2 Optimal care transitions should include pre-hospital discharge activities, immediate post hospital discharge follow up at the next care setting, and should be part of a broader, integrated, multidisciplinary care plan.3

The annual incidence of care transitions from nursing homes [NHs] to emergency departments [EDs] range from 23-60% in the U.S.4 Adults aged 65 years and above account for more than 400 ambulatory visits, 300 ED visits, 200 hospital admission, 46 admissions to SNFs, and 106 home care admissions per 1000 persons in 2000.1

Advancing age and more complex disease are associated with frequent care transitions because of the increased likelihood of co-morbidities, cognitive impairment, increased dependence and polypharmacy; a variety of providers is needed to address the complex needs, which in turn can result in fragmented care, exposure to adverse events, and increased hospital readmissions.5 Seventy-four percent [73.7] of older adults with dementia have a care transition from hospital to NH: the re-hospitalization rate is 23% annually.6 A review of more than 25,000 admissions of Medicare beneficiaries in Rhode Island revealed that patients with dementia were 20% more likely to be readmitted within 30 days of discharge than those without cognitive impairment.7

Care transitions are expected to rise in frequency and complexity as the adult population ages3 and as older adults increasingly use SNF for the recovery of independence.4 The care transition to and from SNF is supported by appropriate communication of health information between these healthcare settings.8

CARE TRANSITIONS
Care transitions are generally preceded by a change in an individual’s condition that triggers an evaluation for possible transfer of care to another setting. The OPTIC (Older Persons’ Transitions In Care) study demonstrated that the most common trigger events in the NH setting were falls with injury [30.9%], changes in physical condition [14.7%], and gastrointestinal distress [11.8%].4

Essential elements of effective care transitions that are vital to ensuring quality include providers’ communications regarding discharge planning, preparation of the patient and family for the transition of care, reconciliation of medications, a follow-up care plan, patient education regarding self-management1, and the involvement of patient and family.5 Poorly executed care transitions can result in adverse outcomes or events2, such as fragmented medical care, delayed diagnosis and treatment, medication errors, unnecessary utilization of emergency room and hospital services, and duplication of testing.1 Fear, confusion, and anxiety are often experienced by patients and families, which lead to poor patient satisfaction. The risk for potentially preventable adverse events should be identified at each care transition point and be actively addressed whenever possible to ensure the likelihood of a quality care transition.3
**OUTCOMES OF POOR QUALITY CARE TRANSITIONS**

**Readmissions**

It is known that one in five Medicare beneficiaries discharged from hospitals will be readmitted within 30 days, at a cost of $26 billion annually. Several performance measures aimed at reducing avoidable hospitalizations have been proposed by the Centers for Medicare and Medicaid Services (CMS). In 2010, the Patient Protection and Affordable Care Act imposed penalties related to hospital readmission rates. Penalties reduce Medicare payments to hospitals with higher than average rates of rehospitalization within 30 days of discharge when the hospitalization is for acute myocardial infarction, pneumonia, or congestive heart failure. Penalties are scheduled to increase and the list of conditions to expand in fiscal year 2015. It is estimated that avoiding 5.2% of preventable Medicare readmissions could save approximately $5 billion annually.

Hospitalization of NH residents and hospital readmissions of patients sent to SNFs for acute rehabilitation represent a unique care transition that is affected by many different factors, including both facility and patient specific characteristics. Readmissions from the NH happen most frequently due to infections, fractures, cardiovascular, and gastrointestinal disorders. One study reported that infections accounted for 25% of NH readmissions. Facility characteristics, such as nursing staff patterns, NH size, and percentage of Medicaid and Medicare reimbursed days also influence NH residents’ risk of hospitalization.

Sixty percent of hospital readmissions from NHs were identified as potentially avoidable. Medication errors, infections, and injuries represented the majority of potentially avoidable hospitalizations, indicating that measures aimed at infection control, falls, medication reconciliation, improved inter-provider communication, timely discharge summaries, follow-up plans, and patient and family education on care transitions may help reduce readmission rates.

**Adverse Events**

An adverse event (AE) is defined as harm resulting from medical management rather than from the disease process. About one in five patients discharged from hospitals will experience an AE within 3 weeks of discharge. More than half of post discharge AEs occur because of poor communication among providers, most commonly regarding medications and test follow-up errors. Test follow-up errors, defined as having a test result noted as pending at the time of discharge in the inpatient medical record but not acknowledged in the outpatient chart, have come to the attention of the Agency for Healthcare Research and Quality, as well as to large malpractice insurers. It has been shown that 41% of discharged patients had pending test results, and that a test follow-up error occurred in 8% of discharged patients. Fifty-four percent of patients experienced one or more medication error on admission to hospitals, with 39-45% of these considered dangerous to the patient.

Poor communication between hospital and NH staff, delayed, inaccurate, or missing discharge summaries on discharge, lack of medication reconciliation, pending test results, lack of a follow-up care plan, and poor education of patient and family regarding expectations at the next care setting are the most common reasons contributing to AE occurrences during care transitions. Patients with low health literacy, non-English language speakers (or English as a second language), who have cognitive impairment, limited social support, and a lack of resources, further contribute to the likelihood of an AE occurrence. Healthcare system-specific barriers, such as specialty care provided in silos, create further ambiguity about who is responsible for the patient; these factors lead to fragmented care and also possibly increase AE occurrence.

**INTERVENTIONS TO IMPROVE CARE TRANSITIONS: NATIONAL**

Interventions to improve care transitions often focus on readmission rates and cost containment for inpatient services, but there are domains in which beneficial interventions, such as care effectiveness, minimizing AE, reducing stress of residents, families, and staff, timeliness, and patient- and family-centered care could improve care transitions. Interventions include profession-oriented interventions, organizational interventions, and patient-family interventions.

To aid in the development of profession-oriented interventions, the Transitions of Care Consensus Conference (TOCCC), which aimed to create successful care transitions, developed standards for the transition of care. TOCCC standards include coordinating clinicians, providing a care plan/transition record, having standard communication formats, accounting for transition responsibility, timeliness, community standards, and including patients and their families in the transition process. The TOCCC standards insist that clinician communication happen whenever patients are at a transition of care. The standards list a minimal set of data elements that should be part of the transition record or discharge summary, including the principal diagnosis, problem list and medication list, the name of the transferring physician, the patient’s cognitive status and all pending tests.

It is important to realize that discharge summaries may be the only information regarding hospital events, medication changes, follow-up appointments, and pending tests that a provider in the community or NH has about a discharged patient. However, 75% of primary care physicians have not received a discharge summary by the first post-hospitalization visit, and often discharge summaries are incomplete or inaccurate, leaving providers at a total loss. The Community–based Care Transitions Program (CCTP) is an organizational intervention created by the Affordable Care Act to improve quality of care and reduce readmission rates for high-risk Medicare beneficiaries. Community involvement is encouraged through formation of
community-based organizations (CBOs) that will use care transition services to manage Medicare patients’ transitions and improve the overall quality of care.9

Patient-family interventions are also of high value, as these individuals often wish for more education and a coordinated approach to care transitions.2 Patients and families are often left uninformed about what to expect, often feel that transfer was initiated too early and note a lack of preparedness for the transition from total care at the acute care site to near self-care at the NH.2

RHODE ISLAND

Healthcentric Advisors (the Medicare Quality Improvement Organization for Rhode Island) developed Safe Transitions Best Practice Measures for improving care transitions of NH residents.20 This project created statewide standards for cross-setting care transitions, resulting in sustainable systems change and overall improved patient safety.20 These standards have been widely accepted and incorporated into health plans across multiple care settings. They have contributed to a decrease in the readmission rate of 8.7 per 1000 Medicare beneficiaries, reflecting 1086 fewer patients admitted to RI hospitals with a $10.4 million cost avoidance over the last 3 years.20 In addition, RI has a mandated continuity of care form that has led to dramatic improvement in cross-setting communication since inception in 2009, and our readmission rates have been dropping rapidly [20% decline in the last three years].

CONCLUSION

Poorly executed care transitions have been associated with increased hospital readmission rates, increased AEs, poor patient satisfaction, and negative overall patient health outcomes. Older adults, and NH residents, in particular, are identified as especially vulnerable, and at risk for increased health care transitions, hospital readmissions, and AEs. In RI, patients with dementia, who account for the majority of NH residents, are responsible for 20% of 30-day readmissions. Interventions aimed at improving care transitions should be implemented at every care transition point, and should follow the standards set out by the Transitions of Care Consensus Conference (TOCCC). Adherence to these standards will result in improved coordination and communication of clinicians, comprehensive discharge summaries, timeliness, as well as education and inclusion of patients and their families in the transition process.

<table>
<thead>
<tr>
<th>Table 1. Safe Transitions Best Practice Measures, Rhode Island</th>
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<tbody>
<tr>
<td><strong>Best Practice #1</strong></td>
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<tr>
<td>This instruction should include the reason for the NH stay, all medication changes, recommended follow-up appointments and tests, and condition-specific “red flags” to prompt the resident to seek attention.</td>
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<tr>
<td><strong>Best Practice #2</strong></td>
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<tr>
<td>Information should include the resident’s baseline status, reason for referral, medications, advance directives, and phone number connecting the ED to nursing home (NH) staff who can address questions about resident.</td>
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<tr>
<td><strong>Best Practice #3</strong></td>
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<td>Clinical or clerical NH staff should be readily available to address the ED or hospital clinicians’ specific questions regarding the transferred resident.</td>
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<tr>
<td><strong>Best Practice #4</strong></td>
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<tr>
<td>Medication reconciliation includes the review of the patient’s discharge medication regimen, comparing the discharge medication regimen to the prior medication regimen to identify and resolve any discrepancies.</td>
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<td><strong>Best Practice #5</strong></td>
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<td>A framework for inter-provider discussions is recommended to ensure high urgency concerns are addressed efficiently.</td>
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<td><strong>Best Practice #6</strong></td>
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<td>Conversations should take place regarding end-of-life topics such as comfort care, do not hospitalize, hospice, general goals of care.</td>
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<tr>
<td><strong>Best Practice #7</strong></td>
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<tr>
<td>Education should incorporate the testing of resident’s understanding, and should include the reason for the NH stay; also includes medication changes, recommended follow-up appointments and tests, and condition-specific “red flags” to prompt the resident to seek attention.</td>
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<tr>
<td><strong>Best Practice #8</strong></td>
</tr>
<tr>
<td>This instruction should include the reason for the NH stay, all medication changes, recommended follow-up appointments, pending test results, and condition-specific “red flags” to prompt the resident to seek attention.</td>
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<tr>
<td><strong>Best Practice #9</strong></td>
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<tr>
<td>The appointment should indicate the date, time, location, and contact info for any questions.</td>
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<td><strong>Best Practice #10</strong></td>
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<tr>
<td>This information should include a contact number to connect the NH staff to outpatient physicians for questions.</td>
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<tr>
<td><strong>Best Practice #11</strong></td>
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<tr>
<td>Residents must receive enough medications after NH discharge until the end of the intended treatment course or until the first outpatient follow-up.</td>
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Acknowledgments
Stefan Gravenstein, MD, MPH, Professor of Medicine; Interim Chief, Division of Geriatrics and Palliative Care, Center for Geriatrics and Palliative Care, Case Medical Center for his expert opinion and edits.
Richard Besdine, MD, Professor of Medicine; Director, Division of Geriatrics and Palliative Medicine; Greer Professor of Geriatric Medicine, Alpert Medical School of Brown University; Professor Health Services Policy and Practice; Director, Center for Gerontology and Health Care Research, Brown University School of Public Health, also provided helpful editorial comments.

Disclaimer
The views expressed herein are those of the authors and do not necessarily reflect the views of any other party.

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Disclosures
None

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April 2015 Rhode Island Medical Journal 18
Health Care Transitions: Perceptions from Older Patients in Rhode Island

RENÉE R. SHIELD, PhD; KALI S. THOMAS, MA, PhD; RACHEL RATCHFORD, ScB

ABSTRACT
Health care transitions are often dangerous for older patients. Interviews with older adults about their health care moves in Rhode Island (RI) were conducted to develop an Internal Medicine (IM) curriculum designed to provide IM interns with insights about the impact of transitions on patients. This paper describes some ways patients talk about their transitional experiences. Following pilot interviews, 10 nursing home residents were interviewed about their care transitions, conversations with physicians, and advice to doctors beginning their careers. The interviews were analyzed to identify themes. Patients described multiple moves, often did not know what to expect, appreciated help from a family member and desired effective communications with physicians. Learning about patient experiences may help new physicians appreciate the experiences of transitions on patients.

KEYWORDS: transitions of care, patient experiences, nursing homes

INTRODUCTION
Problematic transitions plague the experience of older adults in health care. Our rapidly aging population is at risk from a fragmented system of care in which transitions among sites of care are poorly conducted, and experiences of older adults can be of secondary consideration. Transitions among sites of care, even when appropriate, are linked to increased incidence of delirium, hospital-acquired infections and falls, and the exacerbation of pre-existing chronic conditions. Recent literature indicates that more research is needed about these transfers, and that improved communication and education among and by providers is key.

There is increased interest in measuring patient satisfaction with hospital care during hospitalizations; however, since little is known about the patient perspective regarding transitions in sites of care, experiences of older adults must be better understood. Interviews can be effective in revealing aspects of health care that are otherwise difficult to quantify. During medical school, students may be exposed to principles of patient-centered care, the importance of communication, and in some cases, the dangers inherent in care transitions; however, these priorities are challenged after medical school by the exigencies of hospital routines and requirements. The purpose of the research was to use the patient perceptions of their transition experiences to develop a 3-hour curriculum with Internal Medicine (IM) interns on the impact of these transitions.

This paper describes these recollections, focuses on how patients perceived what happened to them and includes some ways patients would like physicians to speak with them. A separate paper, forthcoming, describes the development of the IM curriculum.

METHODS
Three nursing homes (NH) in RI agreed to participate in this project. The administrator, director of social work (SW) and director of nurses (DoN) of each facility helped identify NH residents who might be willing to participate. Six pilot interviews were conducted with recently hospitalized NH residents who the SW or DoN of the NH determined to be cognitively intact; these were followed by interviews with 10 community-dwelling older adults undergoing rehabilitation in a skilled nursing facility (SNF) following a hospitalization. The project was explained to all respondents through an informed consent process. The respondents were asked to recall the reason for hospitalization and to relate events regarding transfers to and care in the emergency room (ER), hospital, skilled nursing facility (SNF) and any conversations they remembered having with physicians. Interviews were audio-recorded and transcribed, then analyzed for themes. The research was reviewed by the Brown University Research Protections Office and determined to be exempt.

RESULTS
After the pilot interviews were completed, we decided to conduct subsequent interviews with community-dwelling individuals who had recently been hospitalized and were now undergoing rehabilitation in a SNF. Of these, one respondent was 61 years old, three were in their 70s, and 6 were in their 80s. All but two respondents were female. A few prominent themes from the interviews are discussed below with illustrative quotes from the respondents.
Respondents describe multiple moves
Multiple moves were common occurrences related in interviews. Some respondents had transfers beyond those from home to the ER, admission to the hospital, and eventual transition to the SNF. For example, one went to a local urgent care facility, then a hospital ER before admission to the hospital and transfer to the SNF. Three went to two hospitals after the ER. One was admitted to the hospital, then went to the intensive care unit and then back to a hospital floor before entering the SNF. After admission to the SNF, a few then experienced moves within the SNF. The following excerpts are examples of recollections of ER and hospital experiences. This respondent had positive memories:

“[All I] remember is the fast ride, sirens going and feeling this blood coming out of my legs you know. It just seemed like one big drama, personal drama anyway. And I don’t know, I wasn’t worried about it…They were so friendly…and they weren’t the least bit afraid [of] this bleeding patient…I realized this is not a big thing to those who are taking care of me…because they were so relaxed…I began to relax.”

An 87-year-old participant described caring ambulance drivers: “Their personality and the way they treated you, you know. Like you wasn’t just a nothing and they treated you with compassion and very nice.” In the ER,

“The team of people just…started hooking you up to IVs …And there was a lady doctor, very very nice…they had to take all these tests and x-rays. [The doctors] didn’t have too much to say. They were just asking the same questions like, ‘What happened!’ ”

However, another who recalled being in a great deal of pain said she was given a call bell to use in the ER. “They kept saying, ‘It’ll just be a minute.’ This was obviously a lie; it wasn’t just a minute. But nobody would pay attention to the fact that I was uncomfortable.” She noted that despite the staff’s “Ooey gooey speech” designed to be reassuring, they “really didn’t care and I was just part of the problem… and they weren’t the least bit afraid [of] this bleeding patient…I realized this is not a big thing to those who are taking care of me…because they were so relaxed…I began to relax.”

Two respondents moved from one hospital to another. One’s daughter was instrumental in this decision. The 78-year-old respondent said, “Just do it.” The daughter retrieved the respondent’s belongings from the hospital and made sure the medications were correct. “My daughter took care of things.”

Respondents often did not know what to expect
Confusion and/or not knowing what to expect was another refrain heard in these interviews. One respondent said, “I really didn’t know. I was just in ‘blah’, and I was kept thinking, where am I gonna go?” Another similarly recalled what may have been delirium:

“I had a really scary experience of not knowing what I was, who I was, or what was going on. It was scary frightening…I kind of went into la la land…It was really weird, and then they assured me that this…happens because of the pain medication…it was this terrible experience I had of being somewhere else, me being someone else. Just disoriented… I felt very much alone…”

Some wanted more information than they remembered was given. One respondent said, “They didn’t explain hardly anything…I did have questions but they never asked me about questions.”

Another recalled, “What really irritated the hell out of me” was that his wife knew about his upcoming hospital discharge shortly before he did.

[The case manager] said, “Mr. [patient name], you know you’re going to a rehab center!” I said, “Yeah I know. My wife told me. You didn’t have the decency to come down and tell me first! You went around my back!” “Well,” she said, “we were very busy…there was so much paperwork.”

Family members could be very helpful
The assistance of a family member figured in these interviews. A few respondents said they did not involve themselves in decisions about the moves or the care because a daughter was performing this role. For example, one daughter asked the respondent about the choice of SNF, and the respondent said, “Just do it.” The daughter retrieved the respondent’s belongings from the hospital and made sure the medications were correct. “My daughter took care of everything.” Another recalled crying much of the time and relying on her daughter for decisions because she became confused. When asked whether doctors or other providers explained the care, this 87-year-old respondent answered:

“Yes, they did explain. But…you’re not really listening for them. My daughter…really listened to them all…She said, ‘Mom, this is the best place for you because how else can you manage!…until we get to the bottom of [this]…you have to be at the hospital.’ ”

A 78-year-old respondent asked her daughter, “You understand that?”… She said, ‘Yeah, okay Ma.’ And so I just forget about it because I get confused if you get more [information].”
Communication with physicians was described as uneven
Communication with physicians was reported to range in quality and was connected to the advice respondents offered. One enjoyed being the object of concern by her providers:

“I loved it. I like to talk about myself. And they were interested. A couple of them even had good suggestions. And I felt as if we were moving forward, that something was being done.”

Another said:

“The doctors…were very nice talking to me…they were just proper…I liked them…they made you feel at home…They made me sit down, and then they sat down.”

On the other hand, one was frightened by what she recalled was a too-forceful manner in one physician’s recommendation:

“‘If you don’t do this, you will die.’ That really got me…scared the hebegeebes right out of me. It didn’t help matters. It really shook me up.”

Advice for physicians
This respondent wanted the physician to “Put it a different way, you know. Sit my family down and say ‘Look, the blood work is this, this and that.’ But he didn’t do that.” Her advice was to, “Give [patients] the opportunity to talk. Be patient… they’re not hearing everybody, you know?” An 86-year-old woman said simply, “Treat them like they were their father. You know, be gentle.” A 77-year-old respondent said, “They need to be reassuring and not be the master of everything… people have their own way of thinking and organizing themselves. And it’s up to the doctor to pick up on that.” An 83-year-old respondent had this specific advice for physicians:

“Slow down. Just remember we have some physical difficulty…I think I am more with it than most of the patients here. And even I am exhausted by them. The people stand over me too close; if they move too fast, I get out of breath. And I am just physically wiped out. And I am perfectly capable of having a party with a team of doctors, but they’ve got to do it at my pace a little bit…It would be nice if they talked a little bit about our particular backgrounds. …Many doctors make us feel that we’re cute and precious and gee just doing well. But, they don’t think of us as real human beings.”

CONCLUSION
This small sample of interviews reveals how some older patients in RI experienced their care transfers among hospitals and SNFs. Their stories reflect patient vulnerability after a hospitalization with disruptions in sleep and other routines and when pain is common. The quotes remind us that patient and provider perceptions of medical events can be markedly different. Individuals in these accounts described the variety of transfers they endured and their feelings of disorientation and confusion. Respondents had different needs for information and seemed reassured by a family member’s assistance in decisions and advocacy. Their advice to physicians about how they would like to be talked with is a vivid reminder that their perception of communication is a vital element in competent and compassionate care in difficult transitions. Attention to their stories can help improve their care at these vulnerable times.

Acknowledgments
The corresponding author gratefully acknowledges the support of the Picker Institute, Inc. and the Arnold P. Gold Foundation in conducting this project.

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The Goals of Care Conversation: A tool to improve patient care in the nursing home at the end of life

Edward W. Martin, MD, MPH

ABSTRACT

Patients residing in nursing homes may undergo burdensome transitions in care during the final months of life. They may get care they do not want and are unlikely to benefit from. Patients and families may not understand prognosis or the potential benefits of treatment. A “goals of care” conversation can be the critical first step in identifying a patient’s wishes and then developing a plan of care that honors those wishes. When the goal of care is to focus on comfort, hospice can be accessed. Hospice can help ensure that the patient’s final time is spent in comfort and that the family’s needs are attended to both before and after the patient dies.

KEYWORDS: end of life, hospice, communication, advance care planning

INTRODUCTION

Patients residing in nursing homes often undergo burdensome transitions in the final weeks and months of life. Patients may return to the hospital for care they did not want and were not likely to benefit from. Identifying the patient’s goals, values and preferences and then developing a plan of care based on these can help to improve care in the final weeks of life. A goals of care discussion is the critical first step in determining what care is most likely to benefit the patient in achieving their goals, what care is not consistent with their goals, and what options, such as hospice, would help meet their goals. Common goals of care include: curing disease, avoiding premature death, maintaining or improving function, prolonging life, relieving pain, enhancing comfort, maintaining or improving function, and dying peacefully.

GOALS OF CARE MAY NOT BE STATIC

The goals of care will typically change as an illness progresses. A patient in the nursing home may have experienced a lifetime of medical care with goals that focused on curing illness and prolonging survival. Patients may have endured discomfort and, at times, suffering to achieve these goals. They may come to a point where cure is not possible and the goals of care may change to maintaining function and independence. As an illness progresses, the goal may then shift to maintaining or improving quality of life and then finally to having a peaceful death. Discussion of goals of care should be held on admission to the nursing home and then repeated at regular intervals, particularly when there are changes in health status.

Before establishing goals of care, it is important that patient and family understand where the patient is in his/her illness. Goals may change significantly as the prognosis is better understood. Research has shown that many patients are unaware of their prognosis. Many patients with heart failure, for example, did not understand that their heart disease would limit their life expectancy. Patients with renal disease on dialysis were much more optimistic about their prognosis than their physicians. Those patients who understood they had a poorer prognosis were less likely to want potentially life prolonging care. Families may not understand that dementia is a terminal illness. Honest discussion about prognosis can begin to address some of these misunderstandings. It is important when outlining prognosis that jargon be avoided. Also vague and evasive comments about prognosis like “only God knows” or “I don’t have a crystal ball” are not helpful, especially when it is clear the patient has a limited life expectancy and is seeking information to inform decision-making.

Concerns are sometimes raised by family or nursing home staff that discussing these issues may be upsetting to the patients. However, it has been shown that patients who have conversations about the kind of care they want at the end of life are not more likely to develop depression than those who do not engage in these types of conversations. They are, however, less likely to get aggressive care at the end of life.

DECISION-MAKING CAPACITY AND GOALS OF CARE

In the nursing home, many patients have dementia and it will be important to assess decision-making capacity. The patient must be able to understand the clinical information, use the information to make a decision and understand the consequences of the decision. If the patient is not able to make medical decisions, the surrogate named in the advance directive will need to be consulted. If a surrogate has not been designated, the family can assist in determining goals.
and making decisions. In speaking to families it is important that they understand the role of surrogate. The family should not be asked what they want done for the patient but instead they should be asked to assist in determining what the patient wanted. This clarification can be critical to alleviate some of the burden that the family may feel. Some may feel that they are being asked to “play God” if they are solely responsible for the decision making process.

When the patient is unable to participate in the discussion, the family or others will need to assist in identifying the goals and values of the patient. Ideally the patient has left an advance directive. This serves two purposes. The document can identify the person the patient has designated to speak for them when they are unable to speak for themselves. It can also help in describing preferences for care in the setting of an advanced illness. The Rhode Island Durable Power of Attorney for Health Care form helps patients to note these preferences. The form presents three scenarios, one when actively dying, the second describing a persistent vegetative state and the third advanced dementia. Given these scenarios, patients are asked to note if they would want a feeding tube or life support. Patients also have the opportunity to describe other wishes or limits they want. This information can be very helpful in guiding the discussion.

The medical history may also provide some clues as to what the patient might want. Family history in many cases simply reads “noncontributory.” It is certainly true that the cause of death of parents of the terminally ill patient is very unlikely to impact the care of the patient. How they died however, often provides important insight into what the patient might have wanted as their death is approaching. If, for example, a parent died after a prolonged hospital stay with multiple unwanted interventions, the patient may have commented on the kinds of things they wouldn’t have wanted in that situation. If a parent died at home among family and friends, this may also have elicited some comments by the patient.

The social history may also have some important information. The number of cigarettes smoked and the amount of alcohol consumed is unlikely to be of great benefit in establishing goals of care. Instead, an appreciation of the kinds of activities that brought quality to the patient’s life can be extremely helpful. The clinician may learn if the patient was someone who valued independence or if they were quite satisfied with a more sedentary and dependent role; these are clues that may help direct the discussion about patient goals and preferences.

DEVELOPING A PLAN OF CARE

Once the patient’s goals and values have been elicited, a plan of care can be developed. When the goal is to have comfort for the final weeks of life, the plan of care will be very different than when the goal is prolonged survival, even if it requires burdensome interventions. Strong physician or practitioner input in developing the plan of care is critical.

One error that is sometimes made in discussing the plan of care is to focus solely on what will not be done (e.g., no intubation, no CPR, no hospitalization). This may leave the patient and family wondering what will happen as they are dying. They will need to be informed how pain, dyspnea, and suffering will be effectively managed and be reassured that care will not be withdrawn.

Patients and families may still have misconceptions about the benefits of various interventions. CPR in particular may be misunderstood. Patients and families may vastly overestimate the success of CPR and may make decisions based on that misinformation. Learning about the futility of this intervention in certain settings and conditions may change the likelihood of requesting it. Benefits of dialysis for nursing home patients may also be misunderstood. It has been shown that most patients residing in a nursing home who begin dialysis will die or have a significant decline in function in the year following initiation of dialysis. Patients receiving chemotherapy or radiation for advanced cancer often do not understand that the treatment is not likely to cure their cancer. Many families may assume that the placement of a feeding tube will benefit a patient with advanced dementia whose dietary intake has declined. Research has shown that the placement of a percutaneous endoscopic gastrostomy tube does not prolong survival.

It is important to assess patient and family understanding of the benefits or the treatment options they are considering, or they may be opting for interventions that are unlikely to help them.

Patients, families, and nursing home staff may not understand the benefits of antibiotics in a dementia patient with pneumonia. Antibiotics are often viewed as a comfort measure by the staff; however, research has shown this is not the case. Patients with dementia who were given antibiotics were actually found to be more uncomfortable than patients who did not receive antibiotics. Antibiotics did however prolong survival of patients with advanced dementia and pneumonia. Again, it is critical to determine what the goals of care are at that point.

THE ROLE OF HOSPICE

If it is determined that quality of life and comfort are the goals of care, then hospice may be helpful in achieving those goals. Research has shown that nursing home residents who receive hospice care are less likely to be hospitalized. It has also been shown that management of pain is better for nursing home resident residents enrolled in hospice than for those not receiving hospice care. Many nursing home residents do access hospice care which can improve the quality of life. Unfortunately for many residents, it is only accessed for the final days of life, often after multiple hospitalizations.

Some dying patients may leave the hospital and go to the nursing home as skilled patients so that Medicare will pay for the room and board. If they go to the nursing home with
hospice care at the routine level, the family will be required to pay the daily room and board rate which can be up to $300 a day or more. Medicaid may cover this cost for those patients who meet eligibility guidelines and established in that state. This creates a disincentive for patients to access their Medicare hospice benefit following a hospitalization. Research has shown that patients who receive skilled care are less likely to use hospice and are more likely to have a short hospice stay, and those patients without hospice in place are much more likely to return to the hospital.

If decisions have been made to limit potentially life-prolonging interventions, the Medical Orders for Life Sustaining Treatment (MOLST) form can be completed. This document ensures that the patient’s wishes for care will be honored if they leave the nursing home for another setting. It includes preferences for CPR, comfort care, feeding tubes, and hospitalization.

For many patients in the final weeks and months of life hospice can provide tremendous benefit not just to the patient but to the patient’s family and caregivers. Hospice can help ensure that the patient final time is spent in comfort and that the family’s needs are attended to both before and after the patient dies.

References

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Disclaimer
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Hospice and Palliative Care in Nursing Homes: Challenges and Opportunities for Enhanced Access

SUSAN C. MILLER, PhD

ABSTRACT
The use of hospice care in nursing homes (NHs) has grown exponentially, but an increasing concern is the lack of access to resident and family-centered palliative care when residents do not elect hospice, and in time periods prior to election. This concern is amplified by the high magnitude of palliative care needs present for NH residents (and their families) when the NH will be their final residence; and, it is amplified because of short hospice stays, half of which are 22 days or less. This manuscript describes the use of the Medicare hospice care in NHs and discusses the policy, staff and physician barriers to timely hospice referral. It also describes the challenges NHs face in expanding residents’ access to palliative care. Opportunities and approaches for increasing palliative care expertise and practice in NHs are presented.

KEYWORDS: Hospice, palliative care, nursing homes, Medicare

INTRODUCTION
This manuscript discusses the barriers to timely hospice care for nursing home (NH) residents and the associated need for expansion of nonhospice palliative care in NHs.

Hospice care provided in NHs is now common. While 14% of dying NH residents nationally received hospice in 1999, in the first six months of 2010, this proportion rose to 40% (see Figure 1); and, in 2010 it was 68% in Rhode Island. This growth in hospice use is believed to be beneficial to NH residents, given the substantial research showing hospice enrollment to be associated with lower end-of-life hospital use, lower use of aggressive end-of-life treatments (e.g., tube feeding, intravenous fluids, other), higher-quality symptom management, and family reports of superior care. However, there are concerns regarding the high rates of short hospice stays and thus the limited exposure to palliative care expertise by residents and their families. In NHs, major barriers to timely referral are the high proportion of residents with chronic terminal illnesses (for which determination of prognoses are difficult) and the use of Medicare Part A Skilled Nursing Facility (SNF) care by terminally ill (often dying) residents who cannot simultaneously choose hospice.

CONTEXT OF HOSPICE AND PALLIATIVE CARE USE IN THE NH
Sixty-three percent of hospice enrollees in 2012 had non-cancer diagnoses, but the proportion was closer to 80% in NHs. Also, 67% of older adults dying with dementia die in NHs. To be enrolled in Medicare hospice, physicians must certify that patients have a six-month terminal prognosis (if the disease runs its normal course). For NH residents with chronic terminal illnesses, and in particular with dementia, the determination of a six-month prognosis is imprecise in practice; research attempting to predict mortality has had only limited success. Given this difficulty and the high prevalence of chronic terminal illness in NHs, hospice NH residents have high proportions of both very short and very long hospice stays. In 2012, for example, the median length of hospice stays was 27 days for patients receiving home hospice compared to 22 days for NH hospice. Still, while 50% of NH hospice patients had stays of 22 days of less, 10% had stays of 335 days or longer, resulting in an average hospice length of stay of 112 days in NHs compared to 90 days for home hospice.

In addition to the above, the admission or readmission...
of NH residents to Medicare Part A SNF care when they are near death or actively dying has a profound impact on Medicare hospice use since Medicare disallows simultaneous hospice and SNF care (if SNF care is related to the terminal condition). Still, 12% of Medicare SNF residents die within 90 days of admission.\textsuperscript{11} Residents admitted or returning to NHs from [3-day] hospital stays qualify for NH SNF care when skilled observation and assessment are required or when they receive therapy or complex services (e.g., intravenous feeding, intramuscular injections, other). There are financial incentives for choosing Medicare SNF care instead of private-pay or Medicaid NH care, and thus there is concern about its inappropriate use. For private-pay residents/families, with SNF enrollment, a substantial Medicare co-payment is received and out-of-pocket expenditures are substantially reduced. For NHs, admission of Medicare/Medicaid [dually] enrolled residents to SNF care translates into NHs receiving the substantially higher Medicare per diem payment instead of the lower Medicaid payment. Research on NH decedents with advanced dementia (i.e., moderately severe to severe dementia) found 40% received Medicare SNF care in the 90 days prior to death. Of these, 30% received hospice compared to 46% of those without SNF care; and, 40% of hospice enrollees (post-SNF) had short hospice stays (\leq 7 days) compared to 19% of those without SNF care. Additionally, 14% of residents with end-of-life SNF care died in a hospital compared to 9% of those without SNF care.\textsuperscript{12}

While hospice eligibility guidelines and Medicare payment restrictions challenge timely hospital referral, other referral challenges exist as well. NH staff practices and knowledge also influence the timing of hospice referral. Through interviews conducted in RI, we found earlier hospice referral was facilitated when NH staff was able to recognize the familiar signs of terminal decline, took initiative in raising and discussing the option of hospice with physicians, residents and families, and when staff believed hospice added value and was not only for the “very end.”\textsuperscript{13} Also, at the time of our study none of the study NHs had written procedures regarding assessment of residents’ prognoses or eligibility for hospice, or for communicating with physicians, residents and families regarding such outcomes. However, according to new CMS surveyor interpretive guidelines,\textsuperscript{14} surveyors are instructed to assess whether NHs have practices in place to regularly assess whether residents are “approaching end-of-life,” and surveyors are instructed to look for evidence that interdisciplinary teams have addressed the discussions and considerations regarding advance care planning needed to clarify residents’ goals and care preferences.\textsuperscript{14}

**Figure 2. “Pocket Care” Information on When to Consider Palliative or Hospice End-of-Life Care**

<table>
<thead>
<tr>
<th>Terminal Indicators, 3&quot;x5&quot;</th>
<th>side 1</th>
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<tbody>
<tr>
<td><strong>WHEN TO CONSIDER PALLIATIVE AND/OR HOSPICE END-OF-LIFE CARE</strong></td>
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<tr>
<td>Palliative and/or hospice end-of-life care can assist with:</td>
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<tr>
<td>• Pain and symptom control</td>
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<tr>
<td>• Emotional, social, and spiritual suffering</td>
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<td>• Home services, medications, nurse case management</td>
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<tr>
<td>• Determining eligibility for additional supportive services</td>
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<tr>
<td>• Facilitating patient and family conferences to define goals of care, including advance directives</td>
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<tr>
<td><strong>ALS</strong></td>
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<td>Rapid progression in last year impaired breathing at rest</td>
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<tr>
<td>Insufficient nutrition/hydration</td>
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<tr>
<td>Recurrent aspiration pneumonia</td>
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<td>Upper urinary tract infection</td>
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<td>Sepsis</td>
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<td>Recurrent fever</td>
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<tr>
<td>Decubitus ulcers</td>
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<td><strong>Coma (any etiology)</strong></td>
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<td>Abnormal brain stem response</td>
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<td>Absent verbal response</td>
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<td>Absent withdrawal to pain</td>
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<td>Serum creatinine (&gt; 1.5 \text{ mg/dL})</td>
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<td>Age over 70 years</td>
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<td><strong>Dementia</strong></td>
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<td>Inability to walk</td>
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<td>Incontinence</td>
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<td>Fewer than six intelligible words</td>
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<td>Albumin=2.5 or decrease PO intake</td>
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<tr>
<td>Frequent ER visits</td>
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<td><strong>Failure to thrive</strong></td>
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<tr>
<td>Frequent ER visits</td>
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<td>Albumin &lt; 2.5</td>
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<tr>
<td>Unintentional weight loss</td>
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<tr>
<td>Decubitus ulcers</td>
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<tr>
<td>Homebound/bed-confined</td>
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<tr>
<td><strong>Diseases with short prognosis</strong></td>
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<tr>
<td>Esophageal cancer</td>
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<tr>
<td>Pancreatic cancer</td>
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<td>Glioblastoma</td>
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<td>Liver cancer and intra-hepatic bile ducts</td>
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<tr>
<td>Gall bladder cancer and extra-hepatic bile ducts</td>
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<tr>
<td>Any cancer with generalized metastases; metastasis to brain, liver, bone; or inoperable</td>
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<tr>
<td><strong>Heart disease</strong></td>
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<td>CHF symptoms at rest</td>
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<td>EF of &lt; 20%</td>
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<tr>
<td>New dysrhythmia</td>
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<td>Cardiac arrest, syncope, or CVA</td>
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<td>Frequent ER visits for symptoms</td>
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<td>**Terminal Indicators, 3&quot;x5&quot;</td>
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<tr>
<td><strong>HIV disease</strong></td>
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<td>CD4+ Count &lt; 25</td>
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<td>Persistent viral load &gt; 100,000</td>
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<tr>
<td>Decreased functional status</td>
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<td><strong>MAC untreated or unresponsive</strong></td>
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<tr>
<td><strong>CNS or systemic lymphoma</strong></td>
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<td>Progressive multifocal leukoencephalopathy</td>
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<td><strong>Visceral Kaposi’s sarcoma-unresponsive</strong></td>
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<td><strong>Renal failure</strong></td>
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<td><strong>Cryptosporidium infection</strong></td>
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<td><strong>Taxoplasmosis – unresponsive</strong></td>
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<tr>
<td><strong>Advanced AIDS dementia complex</strong></td>
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<td><strong>Liver disease</strong></td>
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<td>PT &gt; 5 seconds</td>
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<tr>
<td>Albumin &lt; 2.5</td>
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<tr>
<td>Refractory ascites</td>
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<td>SBP</td>
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<td>Jaundice</td>
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<td>Malnutrition and muscle wasting</td>
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<tr>
<td><strong>Lung Cancer</strong></td>
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<td>Advanced disease stage</td>
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<td>LDH twice normal</td>
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<tr>
<td>Albumen (&gt; 2.5)</td>
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<tr>
<td>Calcium (&gt; 12.0)</td>
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<tr>
<td>Metastases to brain, bone</td>
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<tr>
<td>Decreasing functional status</td>
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| Source: Bailey, Amos. The Palliative Response. (Modified for previous BGSEU/Brown University project.) For more information, go to www.hospice.va.gov/amosbaileybook/
HOW PHYSICIANS AFFECT HOSPICE REFERRAL

Ultimately, residents and their families (and NH staff) rely on physicians for information regarding prognosis, and for referral to hospice. Thus, physician behavior is a key determinant in enabling hospice access. However, several physician-related barriers to timely hospice referral have been found, including lack of knowledge about hospice, negative perceptions of hospice, discomfort communicating poor prognoses, fear of losing control of the patient, and delaying the discussion of hospice until the patient was actively dying.\(^{15-16}\) To assist physicians with determining when palliative or hospice care should be considered, “pocket card” information has been developed (see Figure 2). Also, the American Medical Directors Association (AMDA) has developed a palliative care tool kit to assist physicians in providing optimal care to long-term care residents with chronic and progressive illnesses.\(^{17}\) In particular, this tool kit addresses how “all members of the interdisciplinary team can help physicians become more proficient in the assessment and relief of suffering.”\(^{17}\) As discussed below, surveyor interpretive guidelines address the expected care practices when residents are assessed to be approaching end of life.

For NH residents approaching end of life, the Medicare/Medicaid surveyor interpretive guidelines ask surveyors to determine whether care is driven by resident preferences and is palliative – patient and family-centered care that optimizes quality of life by anticipating, preventing and treating physical or psychological suffering.\(^{14}\) This surveyor guideline pertains to all residents regardless of their hospice status; thus, it intensifies the need for NHs to increase the availability of palliative care expertise to enable assessment and management of residents’ physical and psychosocial needs. Since many RI NHs through their “culture change” efforts have adopted practices and environments enabling patient and family-centered care, they are well-equipped to meet this aspect of the guideline. However, these and other NHs may lack the palliative care expertise needed to ameliorate intractable symptoms such as persistent pain or dyspnea or the staffing or expertise to address residents’ and families’ psychosocial and spiritual needs. NHs can gain this expertise internally through education and training efforts or through selected recruitment; and, it can be obtained externally as discussed below.

Medicare hospice expands the availability of palliative care expertise to NH residents, but for residents unable or unwilling to access hospice and prior to hospice enrollment, other approaches are needed. One approach for expanding access to palliative care expertise is the use of palliative care consults. These consults may be provided by internal NH experts but are also often available to NH residents by external providers [most often through hospice-affiliated organizations].\(^{18}\) Physicians order palliative care consults (often at the suggestion of NH staff) to assist in managing intractable physical symptoms or to assist in addressing resident/family psychosocial needs, including the need for help with end-of-life care decision making. There are no prognostic requirements associated with receipt of palliative care consults, and they can be provided to residents enrolled in Medicare SNF care. Anecdotal findings show the efficacy of palliative care consults in NHs to be promising,\(^{18}\) but there has been little comparative research of their benefits. However, one NH with a NH-staffed consult program found residents with consults had greater reductions in depression and in emergency room visits, compared to its matched residents without consults.\(^{19}\) Also, preliminary findings from our ongoing longitudinal research show that when NHs introduce palliative care consults, their residents’ rates of end-of-life hospital use decrease, compared to rates of NHs who have not yet introduced consults.\(^{20}\)

EDUCATION AND TRAINING EFFORTS

Selective staff recruitment and staff and medical director education and training are other ways for NHs to increase the presence of palliative care expertise. In recent interviews of NH administrators, most cited hospice alone as their only resource for providing staff with palliative care education.\(^{21}\) However, other resources for education and training are available but are certainly not in abundance. Through the End-of-Life Nursing Education Consortium (ELNEC) project a train-the-trainer education program in palliative care was developed, and there is palliative care geriatric curriculum.\(^{22}\) NHs can send a nurse for ELNEC training, and when they return, they can convey this information to other NH nurses and aides. Attendees also have the opportunity to become certified in hospice and palliative care. Also, in addition to AMDA’s palliative care tool kit discussed earlier, other relevant clinical guidelines are available.\(^{23}\) For example, guidelines on pain management and on managing an “acute change of condition” are available.

In addition to the above, quality improvement organizations (QIO) or culture change coalitions in some states have led initiatives to assist in improving NH staff’s palliative care knowledge and practice.\(^{23-24}\) In Rhode Island, for example, the QIO (Healthcentric Advisors) recently conducted a NH palliative care collaborative with staff from 16 facilities. Staff-initiated improvement efforts focused on one of six hallmarks of palliative care: identifying proxy decision-makers, advance care planning, pain assessment, discussion of resident prognosis, discussion of resident goals, and assessment and access to spiritual care. The palliative care collaborative facilitated improvement through staff sharing of information on their change efforts and resulting achievements.\(^{24}\) In addition, other PC education was provided to staff; and 20 NH nurses were funded to attend ELNEC training. A product of this RI initiative is a palliative care toolkit that is available for free on Healthcentric Advisors’ website.\(^{25}\) This tool kit contains a wealth of information including guidance on assessing pain and having resident/family discussions regarding prognoses and goals of care. It also contains links to numerous palliative care organizations and guidelines.
CONCLUSION

While there has been a large increase in hospice use in NHs, many residents still do not access hospice or access it only weeks prior to death. To adequately care for residents with chronic and progressive illnesses, an increase in the presence of palliative care expertise within NHs is needed. This increase can be achieved through earlier hospice referral, use of external palliative care expertise, selected staff recruitment, or by investing in the training and education of staff and physicians. Resources are available to assist in this effort.

References


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Disclaimer

The author has no conflicts of interest to report.

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