

Obstacles to Palliation and End-of-Life Care in a Long-Term Care Facility

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Purpose: This exploratory study used a set of four obstacle constructs derived from both the existing literature and our earlier work to describe the diverse end-of-life scenarios observed for a group of residents in a long-term care facility. **Design and Methods:** Data from a retrospective chart review and both quantitative and qualitative methods of data collection and analysis were used to examine in-depth the end-of-life experiences of all nursing home residents ($N = 41$) who died on the nursing care unit of a large continuing care retirement community during an 18-month period. **Results:** A hierarchy of obstacles to palliation and end-of-life care seems to exist in long-term care settings that begins with the lack of recognition that restorative, rehabilitative, or curative treatment futility has commenced. The next three obstacles in sequence include lack of communication among decision makers, no agreement on a course of care, and failure to implement a timely plan of care. **Implications:** The findings highlight the importance of determining treatment futility as an initial step in the successful delivery of palliative and end-of-life care to residents in long-term care followed by the need for a deliberate and proactive series of actions and care planning processes.

Key Words: Terminal decline, Advance directives, Late life long-term care

In previous work on hospitalization patterns and palliation during the last year of life among a group of residents in long-term care, we found diverse end-of-life experiences on a single nursing home unit. For

some residents, hospitalization was an important trigger for hospice care, which was the first evidence that a shift had occurred from an active curative treatment plan to palliative care (Travis, Loving, McClanahan, & Bernard, 2001). Lengths of time in palliative care modes or formal hospice stay also varied widely. Hospice stays after hospitalization were particularly short (often less than 1 week before death).

The purpose of the present analysis is to take a closer look at the end-of-life experiences for this same group of residents using a set of palliation and end-of-life care obstacles derived from both the existing literature and our earlier work to understand the diverse end-of-life scenarios observed in this long-term care setting. In this study, we report: (a) the frequencies of each of the four obstacles; (b) evidence that a hierarchy of obstacles operates in these long-term care situations; and (c) tests of associations for the obstacles and select background variables, including resident's age, aspects of mental functioning, length of stay in the nursing facility, and hospitalization history in the last year of life.

Obstacles to Palliative and End-of-Life Care

We derived four obstacles to palliative and end-of-life care from our review of the literature and our prior research on end-of-life care in long-term care: (a) failure to recognize treatment futility, (b) lack of communication among decision makers, (c) no agreement on a course for end-of-life care, and (d) failure to implement a timely end-of-life plan of care. A review of the literature that contributed to our conceptualization and naming of each obstacle is provided below.

Failure to Recognize Treatment Futility.—It is often argued that clinicians have difficulty both identifying curative/restorative treatment futility and prognosticating time until death, when residents present with multiple comorbid conditions and advanced age (Gage & Dao, 2000). Identifying treatment futility and making care-limiting decisions for residents who are on long-term care trajectories clearly requires an entirely different approach than, for example, decisions made for previously healthy community-dwelling

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individuals who experience catastrophic and irreversible injury or long-term care residents who are dying of metastatic cancer (Pan & Meier, 2000).

Considerable effort is being made to help clinicians identify individuals in late-life long-term care situations (McAuley & Travis, 2001), that is persons who are approaching endstage disease and will soon commence terminal decline. The problem is that there are both quantitative and qualitative dimensions to terminal decline that are not easily collapsed into simple clinical algorithms and decision-making rules (Shelton, 1998; Wiener, Eton, Gibbons, Goldner, & Johnson, 1998). The quantitative dimension is most often associated with the probability of successfully achieving the desired treatment goal (rehabilitation, weight gain, behavioral management). Low probabilities of achieving treatment goals can result in sequential determinations and ultimately a global determination of treatment futility. In contrast, the qualitative dimension includes various parties' perceived quality of life for the resident, their values, individuals' preferences, and families' wishes. In large part, these two dimensions affect the clinical care of a resident. Despite its conceptual and operational complexity, failure to address and document treatment futility can keep the resident from the "right" kind of care (Rowe, 1996). Therefore, one palliative and end-of-life obstacle to consider is "failure to identify treatment futility."

Lack of Communication Among Decision Makers.—The term *caregiver coalitions* has been used to describe the shift from a traditional dyadic relationship of client-provider to a new client-provider-family triad that is needed as individuals become increasingly dependent and require long-term care (Caplow, 1968; Coe & Pendergast, 1985). This metaparadigm, or global framework (Fawcett, 1984), has been helpful in describing the decision-making process that must occur in long-term care and identifying who must communicate with whom about care decisions and care transitions (Ackermann & Kemle, 1999; Quill, 2000; Travis et al., 2001). A fundamental element of effective caregiver coalitions is that the older person and his or her family members are known by and have an established relationship with the physician (von Guten, Ferris, & Emanuel, 2000) and other providers in the long-term care organization (Travis et al., 2001); thus, all of the coalition members are committed to open communication about treatment plans of care.

Problems in communication can and often do occur with any of the coalition members. For example, a form of resident-physician collusion, previously noted in cancer care (The, Hak, Koeter, & van der Wal, 2000), may exist in which the doctor does not want to deliver end-of-life news, and the resident and/or family members do not want to hear it. The "practice of medicine by telephone" in long-term care in which physicians and family members never or rarely meet face-to-face may also reduce the effectiveness of communication among physicians, the

facility staff, residents, and family members (Kayser-Jones, 1995).

Most families have a difficult time discussing end-of-life and care-limiting issues for a loved one (Basile, 1998; Roberto, 1999). Even when nursing facility residents report discussing preferences regarding care with family members, it is not known how specific those discussions are with regard to the many sequential care and treatment decisions that are required as endstage disease approaches and terminal decline commences (Cicirelli, 2000). Moreover, few physicians are ever made aware of those wishes (Lurie, Pheley, Miles, & Bannick-Mohrland, 1992). If members of the coalition are not sharing information, problems with agreeing on and implementing an effective treatment plan are inevitable (Brechtelsbauer, 2000; Forbes, Bern-Klug, & Gessert, 2000). Therefore, another obstacle to consider is lack of communication among decision makers.

No Agreement on a Course for End-of-Life Care.—Often, family members either will not or cannot choose to forgo aggressive curative care, such as hospitalization or tube feedings for an older relative, because they want to limit the likelihood that they may later feel regret that they withheld potentially effective treatment. "Do everything possible" is a common response to questions about limiting certain types of aggressive/curative care (Travis et al., 2001). As we previously discussed, offering aggressive curative treatment to chronically ill older persons in long-term care often includes uncertainty about both futility and the relative benefit and outcomes of the care.

Regret theory, which holds that decision makers worry about making decisions that in hindsight might prove to be "incorrect" and that they will regret (Djulgovic, Hozo, Schwartz, & McMasters, 1999), is a useful orientation for understanding this behavior. Most people seek to avoid regret in medical decision making. The most effective means to accomplish this goal is enabling decision makers to access information, understand possible treatment outcomes, and clarify the net benefit of a treatment. Failure to address treatment futility and lack of communication among decision makers have a logical, but as yet unspecified, link to this third obstacle in our study, "no agreement on a course for end-of-life care."

Failure to Implement a Timely End-of-Life Care Plan.—The majority of individuals who consider a nursing home their usual place of residence will remain in the nursing facility until death (Zervan, Stearns, & Hanson, 2000). Consequently, the average nursing facility has approximately 29 deaths a year, which represents more than 25% of its mean number of beds (Moss, 2000). Even with this well-documented pattern of living and dying in long-term care that affects large numbers of residents annually, decisions to shift from curative/restorative to palliative care (comfort and symptom management) are often made only after hospitalization or a serious exacerbation of a

chronic condition (Ackermann, Kemle, Vogel, & Griffin, 1998). Therefore, the final obstacle for our consideration was conceptualized as failure to implement a timely end-of-life care plan.

We suggested in our earlier work that orders for hospice care and similar end-of-life care may be symbolic “medical last rites” (DeJonge, Sulmasy, & Gold, 1999) for long-term care residents and family members (Travis et al., 2001). These approaches to managing end-of-life care can be partially attributed to a general unwillingness to embrace the naturalness of dying in American society (Lawhorne, 1999; Lederberg, 1997; McCue, 1995). But, for purposes of understanding clinical care decisions, it should also be noted that there is no clear evidence about what the “right” time and “right” length of hospice care should be for persons of advanced age with noncancer, endstage chronic disease (American Medical Directors Association, 2000; Miller, Gozalo, & Mor, 2000a; U.S. General Accounting Office, 2000).

What we do know is that hospice is either not ordered at all in nursing facilities (nationally only about 1% of a nursing facility’s residents received hospice care; Gage et al., 2000) or is delayed until very late in the course of care (less than a week before death for almost 25% and 30 days or less for 52% of hospice residents in nursing homes across the United States; Miller, Gozalo, & Mor, 2000b). This very limited approach to end-of-life care in long-term care facilities is probably inadequate.

For example, there appears to be “value-added” care in nursing facilities when hospice care is provided. The enhancements include reports of increased quality of life for residents at the end of life, reduced hospitalization patterns, improved pain control, and reduced restraint use (Miller et al., 2000a). The caveat is that a resident must receive hospice care for at least 30 days to minimally experience beneficial effects (Miller et al., 2000a).

The weak penetration and duration of hospice care in nursing homes is an ongoing matter of concern for many groups involved in end-of-life care (National Hospice and Palliative Care Organization, 2000). In the future, refined benchmarks for hospice lengths of stay in long-term care will surely be available. In the meantime, given the lack of well-defined and widely accepted care parameters, we used the empirically derived criterion of “timely” end-of-life care as a hospice stay of at least 30 days (Miller et al., 2000a).

Of course, formal hospice care is not the only way to provide long-term care residents with palliative and end-of-life care. There will always be residents and their families who opt not to receive hospice care, and nursing facilities that choose not to participate in hospice contracting. Hospice teams are equipped with highly specialized knowledge and skill in symptom management and comfort care. But, many long-term care facilities also tout such patient care skills. The important factor is whether the resident has a timely plan of care (30 days of hospice directed or in-house palliative care) that supports his or her end-of-life needs and comfort care.

Methods

Design

A retrospective study design was used that included medical chart reviews and the creation of case summaries for a group of recently deceased nursing home residents. To place the events of the residents’ last years of life in the context of their entire institutional histories, the complete medical record was reviewed for each resident’s entire length of stay. Institutional Review Board approval for the study was obtained from the University of Oklahoma Health Sciences Center.

Setting and Sample

As described in our previous work (Travis et al., 2001), the cooperating organization was a private, nonprofit continuing care retirement community (CCRC) in the southwestern United States. The community included 20 duplexes, 209 apartments for independent living, a 45-bed assisted living center, and a 60-bed nursing facility. Most of the residents in the nursing facility were lifecare residents of the retirement community. Occasionally, residents were admitted from outside the CCRC on a private pay basis. Medicare and Medicaid reimbursements were not accepted by the facility.

At the time of the study, the administrator, director of nursing, and assistant director of nursing were all registered nurses with substantial long-term care experience. Although a formal academic affiliation with a medical school was not in place, several admitting physicians were influential in both state and national medical societies and/or were affiliated with a nearby Health Sciences Center. In addition, the CCRC had a formal collaborative agreement with a local College of Nursing for innovations in practice, education, and research.

The sample ($N = 41$) consisted of all nursing home residents who died during the 18-month period from January 1, 1998 to June 30, 1999. Deceased residents ranged in age from 76 to 102 (mean = 87). Consistent with other institutionalized long-term care populations, they were predominately female (85.3%) and widowed (85.4%). Sixty-one percent had a diagnosis of dementia on their medical records. The residents in the sample resided on the nursing unit from as little as 2 days to as much as 3,114 days until death occurred either in the facility or in a hospital (mean = 704, median = 390). Most of the residents (90.2%) had a living will and/or a do not resuscitate order on their charts. This percentage is much higher than the approximately 60% reported for the general nursing facility population in both multistate (Teno et al., 1997) and national (McAuley & Travis, 2001) studies of advance directives in long-term care.

The person to be called in case of emergency was usually an adult daughter or son (75.6%). In all but four cases, these same individuals were listed as the responsible party for the residents’ care and also held Durable Power of Attorney for decisions regarding

the residents' health care. Eighty-five percent of these responsible parties lived in state. Four residents were listed as their own responsible party and were considered capable of making decisions for themselves.

Data Collection

The original data upon which the current analysis is based included both quantitative (Phase 1) and qualitative (Phase 2) methods of data collection. Because a complete description of the data collection procedures has been previously reported (Travis et al., 2001), the multiple phases and steps are presented in summary form in Table 1.

Operationalization of Study Variables From the Qualitative Data

Our operationalization of the four-obstacle variables is an extension of previous work with the data in which we classified each resident as being in palliative or nonpalliative care modes at the time of death (Travis et al., 2001). Below is a description of how each palliative care obstacle was operationalized for the current analysis.

Failure to Address Treatment Futility.—Accepted documentation in the medical record that the resident's condition was being monitored for treatment futility included a note in the interdisciplinary plan of care that the resident's condition was poor and recovery was not an expected outcome (*implicit palliative care*) or a progress note by the physician and/or an occupa-

tional or physical therapist stating that the resident's rehabilitation potential was "poor" (*implicit palliative care*). Conversely, "failure to address treatment futility" was defined as the absence of such notes at any time during the last 12 months of life. Our rationale for this rather strict operational definition was that, even though the professional members of the care team may think about futility issues in their approaches to care, if these assessments were not documented they were not providing reliable guidance for palliation and end-of-life care for the entire interdisciplinary team.

Lack of Communication Among Decision Makers.—We searched for evidence that the responsible parties were engaged in open communication with the resident, physician, and team members. Documentation of attendance at care planning conferences or discussions with family members about care issues that were noted in physician or social service progress notes, nurses notes, or team care planning notes were considered acceptable criteria for establishing communication about end-of-life care. Lack of communication was recorded for those cases in which no such documentation could be found in the medical record for the last 12 months of the resident's care.

No Agreement on a Course for End-of-Life Care.—For this variable, we considered three sources of documentation: (a) a physician's note to the effect that the resident and/or responsible party understands that cure is not possible and requests or agrees to "comfort care" (*explicit palliative care*), (b) a medical order for hospice care (*explicit palliative care*), or (c) a social service or care planning team note that the resident or family made their wishes known and the staff were prepared to follow the specified course of palliation and end-of-life care (*explicit palliative care*). Absence of these explicit notes regarding a course of care constituted "no agreement on a course for end-of-life care."

Failure to Implement a Timely End-of-life Plan of Care.—A timely plan of care was defined as either the implementation of hospice care or other end-of-life palliation plans that occurred at least 30 days before death (or for the duration of the nursing facility admission if less than 30 days) or offers for hospice or other palliative care interventions that were refused by the resident or responsible party. Absence of either of the above was considered "failure to implement a timely end-of-life plan of care."

Data Analysis

Descriptive statistics were used to summarize the quantitative data. The documentation retrieved from the chart reviews and the subsequent resident case summaries provided the data needed to operationalize the four-obstacle constructs. Each obstacle was scored as "one" if the obstacle was present (no recognition of treatment futility, lack of communication,

Table 1. Description of Data Collected Using Quantitative and Qualitative Approaches

Phase 1—Quantative Data
Step 1—Pretest of instrument using current residents' records
Step 2—Medical record reviews of deceased residents to collect information about:
<ul style="list-style-type: none"> • Demographic information • Medical conditions • Hospitalization • (Implicit or explicit) palliative care designation • Functional status • Medication histories
Phase 2—Qualitative Data
Step 1—First reading of all "notes" in the medical record to create a picture of the:
<ul style="list-style-type: none"> • General course of care and critical events in the last year of life • Timing of advance directives and individuals involved in decision making • Trends in the resident's decline over time
Step 2—Second reading of notes around critical events to determine:
<ul style="list-style-type: none"> • Awareness of the event by team members • Conflicting perspectives of the event • Care during the final critical event, the death experience
Step 3—Data organized into case summary narratives for presentation to and verification by the care planning team

no agreement on plan of care, failure to implement timely plan of care) or “zero” if the obstacle did not exist. The total number of obstacles was also summed for each case.

A strategy used in previous work (Travis et al., 2001) called concept tables was used to display each of the four-obstacle constructs and the total number of obstacles present with selected resident characteristics (age, relationship of designated responsible party to the resident, length of stay in the nursing facility). Access to the complete case summaries, scores for each failure construct, and resident information allowed the team to move back and forth from inductive to deductive reasoning as we worked with the data. Chi-square tests of independence and correlation coefficients were used to test “hunches” about possible associations among the variables, as suggested by the existing literature and our work with the data. Because of the relatively small sample size, a .10 significance level was used.

Results

The Four Obstacles

As shown in Figure 1, there is a logical and conceptually meaningful relationship between the probability of terminal decline and the appropriateness of palliative and end-of-life care. It is along the line created by the intersection of these two conditions that we conceptualized obstacles to care. Forty-six percent ($n = 19$) of the cases had no obstacles to their pallia-

tive and end-of-life care. For these cases, recognition of treatment futility, communication among decision makers, agreement on a course of care, and timely implementation of a plan of care were all observed in the medical record documentation. The remaining cases experienced one or more obstacles in their last years of life. Failure to recognize treatment futility occurred in 17% ($n = 7$) of the cases, lack of communication among decision makers was noted in 22% ($n = 9$) of the cases, no agreement on a course of care occurred in 35% ($n = 14$) of the cases, and failure to implement a timely plan of care occurred in 54% ($n = 22$) of the cases.

In an effort to understand how resident characteristics might be related to the individual obstacles and the total number of obstacles, we first considered the residents' ages and lengths of stay in the facility. Our thinking was that older residents or residents with longer lengths of stay might have had more time to work out their palliative and end-of-life plans of care. We found no significant correlations (testing both Pearson correlation coefficients and the nonparametric Spearman's rho) between the residents' ages at the time of death or lengths of stay in the facility, and number of obstacles. Next, we turned to the residents' mental functioning, as documented in the standardized patient assessment database (which is similar to, but not identical to, minimum data set data), to see whether the resident's ability to engage in decision making or to make his or her wishes known had any relationship to the presence of obstacles to care. Cross-tabular analyses with chi-square statistics were

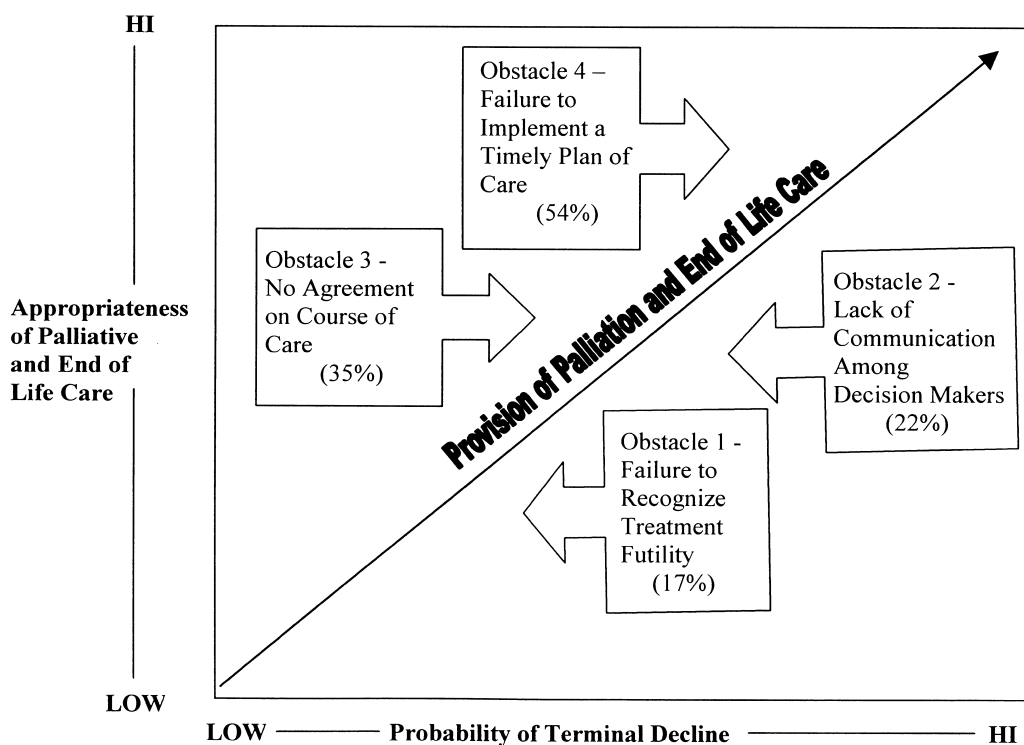


Figure 1. Obstacles to palliation and end-of-life care. Obstacles adapted from a presentation by Sharon Dixon to the Carolinas Medical Center Medical Staff, Charlotte, NC, January 2000.

used to examine associations between the residents' mental status and orientation, ability to communicate, ability to participate in decision making, and attention to each of the four-obstacle constructs. Once again, none of these associations was significant.

Finally, we considered if having any hospitalizations in the last year of life was associated with obstacles to palliation and end-of-life care. This analysis demonstrated that residents who were hospitalized were more likely than their nonhospitalized counterparts to have one or more obstacles identified in their end-of-life care ($\chi^2 = 3.103$, $df = 1$, $p = .078$).

An Emerging Hierarchy of Obstacles to Care

Of particular interest to the research team was a hierarchy of obstacles that emerged when we examined the obstacles for each case. As shown in Table 2, the four obstacles are displayed on the left-hand side of the table, followed by six distinct obstacle patterns derived from the data. Pattern 1 (second column) represents those cases (46%) in which no obstacles occurred in care. If only one obstacle was present (third column, Pattern 2), it was failure to implement a timely plan of care (Pattern 2). Two obstacles (fourth column, Pattern 3) represented no agreement on a course of care and failure to implement a timely plan of care. Three obstacles (fifth column, Pattern 4) consisted of lack of communication among decision makers, no agreement on a course of care, and failure to implement a timely plan of care. A full 93% ($n = 38$) of the cases followed one of the first five patterns presented in Table 2. These obstacles are displayed in hierarchical order in Figure 1.

Seven percent ($n = 3$) of the cases that did not fit one of these patterns (seventh column, Pattern 6 on Table 2) all had the same alternate pattern, which consisted of failure to recognize treatment futility, lack of communication among decision makers, and failure to implement a timely plan of care. The "out-of-sequence" action in this pattern, agreement on a course of care, occurred even though documented recognition of treatment futility and evidence of communication among decision makers could not be found. Reviews of these three cases suggest that the family decisions to limit care occurred abruptly, with no evidence of a planned and systematic approach to the

resident's end-of-life care. The decisions to limit care and to request hospice care for these three cases came 5 days or less before the death of the resident. Consequently, the operational definition for the timely implementation of a plan of care was also not met.

Discussion

The provision of palliation and end-of-life care is a complex process involving multiple junctures at which good, bad, or ineffective actions can occur. In this analysis, we conceptualized a preliminary set of obstacles that might limit appropriate movement through these junctures. We discovered two important sets of findings about these obstacles.

Our finding regarding a hierarchy of obstacles to palliation and end-of-life care was intriguing from both theoretical and applied perspectives. Returning to Figure 1, it can be seen that we have placed our obstacles in the hierarchical order of their impediment to palliation and end-of-life care. The obstacle hierarchy begins with the lack of recognition that treatment futility has commenced. For a number of well-documented reasons (Travis et al., 2001), clinicians are reluctant to make this determination in a regulatory climate that favors curative, rehabilitative, or restorative care over palliation and end-of-life care. Failure to prognosticate futility is the most powerful obstacle to effective palliation and end-of-life plans of care in our long-term care sample, because if this obstacle is present, it is almost inevitable that the other obstacles will follow. However, it would be misleading to emphasize this obstacle over all others, when only 17% of our cases experienced failure to recognize treatment futility.

Instead, the two most prevalent obstacles in our analyses suggest that the really difficult work in end-of-life care involves agreeing on and implementing a course of care. Fifty-four percent of our sample experienced one or both of these obstacles. It may be the case that the current approach to advance care planning occurs at a time, such as admission to long-term care, when the end of a resident's life is evidently a distant and incomprehensible event. When faced with end-of-life decisions in "real time," an entirely different decision-making process is needed to guide care. Helping residents and family members agree on a

Table 2. The Obstacle Hierarchy

Obstacles	Pattern 1 (no obstacles) (46%)	Pattern 2 (12%)	Pattern 3 (20%)	Pattern 4 (5%)	Pattern 5 (all obstacles present) (10%)	Alternate Pattern 6 (out of sequence) (7%)
1 (Recognize treatment futility)	0	0	0	0	1	1
2 (Communication)	0	0	0	1	1	1
3 (Agreement on course of care)	0	0	1	1	1	0
4 (Timely plan of care)	0	1	1	1	1	1

Note: 0 = obstacle not present; 1 = obstacle present.

course of care, implement the plan in a timely fashion, and stay the course of care requires a very high and intense level of engagement among decision makers. Clinicians and care planning team members understand aggressive curative or restorative care, but aggressive palliative care has not yet been universally incorporated into standards of care for residents at endstage disease. Although the “active curative care” versus “no definable care” dichotomy is changing (Travis, 2001), there is historically a several-year lag between innovations in practice and practice changes in the real world. Removing these two obstacles will no doubt be challenging, which leads us to a discussion of the second set of findings.

There is no apparent relationship between the resident’s ability to communicate or to participate in decision making and obstacles to palliation and end-of-life care. There is also no apparent relationship between a resident’s age or length of stay in a facility and the number of obstacles to care that he or she will experience. What does seem to be important is how the resident’s medical condition is managed. Specifically, residents who are hospitalized during what we now know was their last year of life are also likely to have experienced one or more obstacles to their end-of-life care.

Perhaps it is time to acknowledge that hospitalization at the end of life is the “canary in the cage” for monitoring end-of-life care in long-term care facilities. There are at least two separate, although interrelated, aspects of the hospitalization/palliation and end-of-life care issue that specifically relate to the current study.

As we described in the review of the literature, hospitalization may be the clinician’s only option in response to a resident’s terminal decline, if advance care planning was not or could not be addressed with the resident or family prior to the need for hospital care. Under current practices, the admitting physician may not even be physically present at the time the resident is admitted to the nursing facility. If a resident is new to the admitting physician, it may take some time for the physician and facility team to gather and assimilate all of the relevant information about the resident and his or her expressed wishes for end-of-life care beyond the basic elements of advance care planning that may appear in a living will. When conflict about care and treatment decisions arise, physicians vary widely in how they communicate with their patients (and family members) to resolve treatment conflicts in a timely way (Fetters, Churchill, & Danis, 2001), and families vary widely in their receptivity to these communications.

It may also take a hospital admission for the clinician, resident, and family members to understand, recognize, and agree that the resident is truly in the terminal phase of life. For example, the requirement that resuscitation status be addressed with each hospital admission forces decision makers to consider whether the resident is or could be approaching terminal decline, and what actions are most appropriate and desirable.

Remedies for improved palliation and end-of-life care will probably require a series of changes in long-term care practice. For example, uniform expectations that scheduled team meetings regularly consider explicit end-of-life care discussions with key decision makers would ensure all residents of end-of-life care considerations. When face-to-face team meetings are not possible for working or long-distance family caregivers or physicians at off-site locations, telephone conference calls may be necessary. Printed information about end-of-life choices and decisions needs to be consistently supplemented with expectations for personal follow-up to provide ample opportunity to discuss end-of-life care preferences on regular and updated intervals. In other words, expectations for end-of-life care planning that include passive engagement strategies will need to be replaced by expectations for active and ongoing engagement by all members of caregiving coalitions in long-term care.

The four obstacles in our hierarchy probably do not represent all of the possible obstacles to palliation and end-of-life care in long-term care. Other obstacles, such as environmental limitations to providing certain types of care and reimbursement/financial considerations, were not considered in this study, because the data came from only one private-pay retirement community. We recognize the atypical nature of this class of nursing facility (affiliated with a private CCRC) and the limited generalizability of our findings. Clearly, the present obstacle hierarchy needs to be validated in other nursing settings, and other obstacles—which could also be powerful impediments to care options and choices in other types of nursing facilities—need to be identified.

The present retrospective review of the courses of care of residents who died in long-term care also had two major contextual limitations, which we need to acknowledge. First, we accepted only those elements of care that were documented in the medical record. Because this document is notoriously incomplete, some discussions among and decisions by key individuals in the caregiver coalitions may not appear in the medical records. Second, the research team was blind to the wishes and expectations of residents that may have been discussed years in advance of the need for end-of-life care. Therefore, our view of the care planning process and the associated decisions was also limited.

Longitudinal studies that follow the transitions in care of long-term care residents and the decisions that residents and family members make about care would most likely provide important additional information that could not be captured by our extant chart data. Future research also needs to become increasingly linked to conceptual frameworks that begin to relate important variables to each other. The volume of atheoretical research on end-of-life care that currently exists in the literature overwhelms the handful of studies that are conceptually driven. Findings such as our preliminary obstacle hierarchy are necessary to lay a sound conceptual foundation on which to launch larger scale, multisite confirmation studies and subsequent

empirically and theoretically driven intervention/demonstration projects.

In conclusion, except for residents who die unexpected deaths, any resident of an advanced age who is permanently placed in an institutional long-term care setting should not die without a plan to direct his or her end-of-life care. Given what is known about the importance of symptom management and comfort care at the end of life (Faull, Carter, & Woof, 1998; Lynn, Schuster, & Kabcenell, 2000), this plan of care should be guided and evaluated by defensible standards for palliation and end-of-life care. Understanding the obstacles to implementing effective plans of care is an important step toward this goal.

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