Hospitalization Patterns and Palliation in the Last Year of Life Among Residents in Long-Term Care

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Purpose: This study compared patterns of care, including hospitalization, during the last year of life for a group of residents in institutional long-term care. These subjects were either implicitly or explicitly in palliative care modes versus those who remained in active treatment or blended care.

Design and Methods: The study used a retrospective chart review and both quantitative and qualitative methods of data collection and analysis to examine in depth the end-of-life experiences of 41 nursing home residents who died in the nursing care unit of one large continuing care retirement community during an 18-month period.

Results: Most residents die in palliative care modes, but their movement into palliation with comfort care and symptom management is often slowed by indecision or inaction on the part of key decision makers, interrupted by aggressive acute care, or delayed until the last few days of life.

Implications: Transitions from active curative care to palliative care are important for residents in permanent long-term care placements. Improved end-of-life care requires more attention to these transitions and to the decisions that residents, their families, and care teams are called upon to make.

Key Words: Advance directives, Caregiver coalitions, End-of-life care

In the mid 1970s, efforts to understand transitions in care that would be required for growing numbers of individuals surviving to advanced ages with chronic care needs resulted in the conceptualization of a living–dying trajectory that included intervals for living, living–dying, and dying and death (Pattison, 1977). More recent applications of this continuum to long-term care (LTC) include the suggestion that nearly all permanently placed nursing facility residents enter care in the chronic living–dying interval (Engle, 1998; Lawhorne, 1999; Pattison, 1977). Practitioners and organizations that care for these residents face multiple decision points during the residents’ long-term care. At these times, an assessment of benefits over harmful effects (beneficence) should guide treatment decisions (Rhymes & McCullough, 1994) that are based on an understanding of the resident’s prognosis and placement on the living–dying continuum.

In this article we report: (a) hospitalization prevalence and incidence rates, (b) differences in the timing and duration of palliative care modalities for nursing facility residents who were hospitalized versus those who were not, and (c) aspects of caregiver coalitions that appear to distinguish between residents who were hospitalized and those who were not.

Review of the Literature

Palliation is the term now used to describe care that is no longer aimed at cure or active treatment of medical conditions. Instead, the goals of palliation are resident comfort and symptom management (Mann & Welk, 1997; Post & Dubler, 1997). For some LTC residents with chronic illness, blended care (active treatment with palliation) may last for years with relatively short periods dedicated solely to palliation. For others, such as those with Alzheimer’s disease, it has been argued that palliative care should be the dominant mode of care for the long term (Solomon & Jennings, 1998). When death is imminent, generally in the last 6 months of life, the specialized knowledge of the hospice team, now conceptualized as a component of palliative care, is used for the final transition from dying to death (Mann & Welk, 1997).

One of the more critical junctures in the care of an LTC resident, in terms of both resource utilization...
and quality of life, is when the need arises to make a decision about whether or not to hospitalize the individual. From the increasing amount of information available about these decision points, it is frequently argued that treatment options should be based on where the key decision makers (resident, family, physician, and staff) either explicitly or implicitly place the resident on a living-dying trajectory, such as the one in Figure 1. In other words, more than just the immediate clinical condition of the resident guides interpretations of what comprises “good” or “harmful,” appropriate or inappropriate treatment options.

Figure 1 is a schematic representation of this living-dying trajectory with an additional refinement that adds treatment modalities, including palliative and hospice care, to the righthand side of the figure across from the corresponding intervals in the trajectory. This updated schematic was used to guide our conceptualization of data collection procedures, selection of data analysis techniques, and the interpretation of the results of a project that studied the last year of life for a group of residents in institutional long-term care.

As depicted in Figure 1, acute care is compatible with a need for blended care early in the living-dying interval and may include hospitalization or other aggressive care. As the individual’s condition progresses toward the dying interval, transitional care is used to move from curative care treatment to a plan of palliation for comfort and symptom management. The living-dying interval ends with a commitment to and a plan for palliation with symptom management. Therefore, high rates of hospitalization among residents who are established in palliation and/or hospice treatment modalities would represent potential inconsistencies between actions and prevailing recommendations about palliation and LTC. It should be noted that at no time is “no care” an acceptable standard of care in this schematic. Rather, the mode of care changes as the resident’s condition changes from living through the process of actively dying, in which body functions are beginning to decline and ultimately shut down as death approaches.

When frameworks such as the one shown in Figure 1 are well understood by treatment teams and family members, dramatic reductions in hospital deaths and enhanced end-of-life care in the nursing facility have been reported (Ackermann & Kemle, 1999). Unfortunately, neither the term palliative care nor the associated approaches to care have been well integrated into most LTC facilities. Indeed, from our review of more than 225 journal articles and book chapters, the barriers to fully implementing high-quality, comprehensive palliation in LTC are better documented in the literature than are reports of successful end-of-life programs.

Among other things, the current regulatory climate in LTC settings causes some providers to fear that they will not be seen by nursing home surveyors as sufficiently aggressive in their care if they allow a resident to decline without intervention (Meier & Morrison, 1999). Prognostications and end-of-life staging continue to be difficult and inexact, especially for noncancerous, LTC residents whose progression from curative care to palliation requires a blended type of care for some period of time (Blatt,

### Intervals in a Resident’s Living-Dying Trajectory

<table>
<thead>
<tr>
<th>Interval</th>
<th>Treatment Modality</th>
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<tr>
<td><strong>Living</strong></td>
<td>Active Treatment</td>
</tr>
<tr>
<td><strong>Living-Dying</strong></td>
<td>Blended Care (active treatment and palliative care)</td>
</tr>
<tr>
<td>(point at which most permanently placed residents enter nursing home care)</td>
<td>Hospitalization or Other Aggressive Curative Care May Be Appropriate</td>
</tr>
<tr>
<td><strong>Dying</strong></td>
<td>Transitional Care Concluding with a Palliative Plan of Care Focusing on Symptom Management</td>
</tr>
<tr>
<td><strong>Death</strong></td>
<td>Palliative Care With Specialized Hospice Care to Manage the Final Transition for the Resident and Family</td>
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Figure 1. Living-dying care in long-term care.
Methods

Phase 2 – Qualitative Data
Step 1 – First reading of all notes in the medical record to create a picture of the:
• Care during the final critical event, the death experience
• Conflicting perspectives of the event
• Trends in the resident’s decline over time
• 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:
• 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 the Care Planning Team

Phase 1 – Quantitative Data
Step 1 – Pretest of instrument using current residents’ records
Step 2 – Medical record reviews of deceased residents to collect information about:
• Demography
• Medical conditions
• Hospitalization
• Functional status
• Medication histories
• Palliative care designation

Setting and Sample

The cooperating organization was a private, non-profit continuing care retirement community (CCRC) in the southwestern United States. The community consisted of 20 duplexes, 209 apartments for independent living, a 45-bed assisted living center, and a 60-bed nursing facility, which was the focus of this investigation. Most of the residents in the nursing facility were life-care residents of the retirement community. Occasionally, residents were admitted from outside the CCRC on a private-pay basis. Medicare and Medicaid reimbursement were not accepted by the facility.

The sample consisted of 41 nursing home residents who died during the 18-month period January 1, 1998, to June 30, 1999. Deceased residents ranged in age from 76 to 102 (mean = 87). Consistent with other institutionalized populations, they were predominately female (85.3%) and widowed (85.4%). Fully 61% had a diagnosis of dementia on their medical records. The residents in the sample were in care on the nursing unit from as little as 2 days to as many 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 advance directives on the chart. 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

Both quantitative (Phase 1) and qualitative (Phase 2) methods of data collection were used. Table 1 dis-

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

<table>
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<th>Approach</th>
<th>Method</th>
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<tr>
<td>Phase 1 – Quantitative Data</td>
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plays the phases and steps included in the data collection procedures. The initial data collection process took between 45 minutes and 3.5 hours for each case, which was a reflection of the range in lengths of stay and number of hospitalizations.

Phase 1 consisted of two steps. First, the data retrieval tool was pretested using the medical records of three residents who were currently in care. Next, quantitative data were collected from the records of the deceased residents for the last year of life or the entire length of time in the nursing home, if less than one year. The information included the resident’s demographic characteristics, functional status, medical conditions, medication histories, and hospitalization data for each hospitalization.

Phase 2 consisted of three steps. First, the full set of “notes” was reviewed to develop an overview of the resident’s general course of care and to identify critical events, defined as acute changes in the resident’s condition or circumstances that required changes in the plans of care. Elements of the course of care that were noted included: (1) documented exchanges among residents, their family members, the resident’s physician, and the staff regarding care issues (personalized care, quality of care, agreement about specific treatment decisions); (2) the timing of advance directives and individuals cited in the medical records during any decision-making times; and (3) trends in the resident’s decline over time (e.g., spontaneous, rapid or progressive, linear or stair-step). Critical events included, but were not limited to, changes in the resident’s medical condition. For example, the death of a spouse who was the resident’s responsible party and the need for an adult child to become the primary decision maker, as noted in the social service notes, was recorded as a critical event.

In the second step of Phase 2, the date of entry for each critical event was used to guide a second reading of notes that were written before and after the critical event in order to gain the perspectives of all members of the care team. Questions guiding this reading included the following: Did other team members read each summary one at a time, commented on any relevant memories they had of the resident’s care, and verified the accuracy of the summaries.

**Operationalizing Palliative Care**

Because “palliative care” is a term that is not in common use and specific criteria for operationalizing the variable for LTC populations do not exist, a method for determining whether or not a resident was either explicitly or implicitly in a palliative care mode had to be created from existing chart information. We selected criteria that could justify limiting aggressive curative care, such as evidence of functional decline with no rehabilitation potential, and would support decisions for comfort care and symptom management. In addition, a “do not resuscitate” (DNR) order was deemed an essential criterion because without such an order, aggressive treatment (cardiopulmonary resuscitation, activation of 911, and transfer to the hospital) would have been required regardless of any other implicit or explicit evidence of the futility of such intervention that we might have found in the medical record.

Briefly, a resident was classified in palliative care if he/she had a DNR order on the chart and at least one of the following entered in the medical record in the 12 months preceding death: (a) a medical order for hospice (explicit palliative care), (b) a physician’s note stating that the resident and/or responsible party understands that cure is not possible and requests “comfort care” (explicit palliative care), (c) evidence in the interdisciplinary plan of care that the resident’s prognosis was poor and recovery was not an expected outcome (implicit palliative care), or (d) a progress note by the physician and/or an occupational or physical therapist stating that the resident’s rehabilitation potential was “poor” (implicit palliative care).

Because the exact wording of entries in the medical records tended to deviate slightly from the language in the operational definition, the investigators performed a coding reliability check for each case. For this step, the first two authors reviewed the verbatim documentation retrieved from the medical records and independently determined if the case met the criteria for palliative care. They agreed with each other’s coding decisions 100% of the time.

**Analysis**

Quantitative data analysis initially consisted of descriptive statistics to summarize the data. Once the reliability of the case summaries was established, content analysis of the case summaries enabled us to explore possible inconsistencies between treatment modalities and care decisions. Because we were interested in who was involved with care decisions, especially decisions to hospitalize, part of the analyses of these data looked at the concept of caregiver coalitions in long-term care. The term “caregiver coali-
itions” has been used to describe the shift from a traditional dyadic relationship of client–provider to a new triad of client–provider–family that is needed as individuals become increasingly dependent (Caplow, 1968; Coe & Pendergast, 1985). This metaparadigm, or global framework (Fawcett, 1984), was used to help the team focus on who was communicating with whom about care decisions in the last year of life. Access to both quantitative and qualitative data about the residents was important because it allowed the team to move back and forth from inductive to deductive reasoning and to test hunches as we worked with the data. A strategy that we labeled “concept tables” was used to display the concepts of interest (conflicted vs nonconflicted hospital admissions, types of hospital admissions, and caregiver coalitions) with selected resident characteristics. Chi-square tests of independence and t tests were used to test “hunches” about possible associations among the variables, as suggested by the existing literature and our work with the qualitative data.

Results

Hospitalization Prevalence and Incidence Rates

Slightly less than half of the deceased residents (46.3%, n = 19) were admitted to the hospital, for a total of 27 separate admissions, during their last 12 months of life. Two thirds (68%, n = 13) of these residents experienced one admission, 21% (n = 4) were admitted twice, and 11% (n = 2) had three admissions during the 12 months preceding death. In addition to this inpatient care, 26.8% of the total sample (n = 11) had between one and three visits to the emergency room in the last 12 months of life that did not result in hospitalization. Falls with minor injury (lacerations, rib fractures) were the primary reason for these outpatient contacts.

The reasons for the hospital admissions included three broad categories: accidental injury (e.g., fractured hip; 15%, 4 admissions), acute conditions (52%, 14 admissions), and conditions related to end-stage chronic disease (33%, 9 admissions). Over half of the admissions for acute conditions were pneumonia-related. Cardiopulmonary failure represented the vast majority (66%) of the chronic care admissions. There were no statistically significant differences in age or weight loss, a classic clinical indicator of terminal decline, between residents who were hospitalized and those who were not. In order to see if having a diagnosis of dementia, implying reliance on others for care decisions, made any difference in hospitalization patterns, we compared the number of hospital stays for the two groups of residents. The demented residents had somewhat higher rates of hospitalization in the last year of life than their non-demented counterparts (t test = -1.53, p = .067).

Palliative Care Modalities

For the total sample, the overwhelming majority of the residents (87%, n = 33) satisfied the operational definition for palliative care within the last 12 months of life. These residents died in palliative care modes ranging in length of time from 2 days to 284 days. About one third of the hospitalized residents (37%, n = 7) were in palliative care modes at the time a decision to hospitalize was made. Forty-two percent of the hospitalized residents entered palliative care modes following their hospital discharges.

The hospitalization experience was an important trigger for hospice care. About two thirds (63%, n = 12) of the hospitalized residents were discharged with orders for hospice care or were approved for hospice care within 6 months of their last hospitalizations. For one half of this group of residents, the hospice order was the first evidence of a shift to palliative care in the year preceding death. Clearly, a large percentage of residents from LTC were being provided aggressive hospital care. Returning to our initial conceptualization of a living–dying continuum for permanently placed residents in long-term care, it seemed possible that at least some of these cases might represent the cognitive dissonance currently surrounding palliative care and end-of-life care for LTC residents (Zuckerman, 1999). In an effort to better understand the hospitalization patterns identified in the sample, we turned to the case summaries.

The Decision To Hospitalize

A defining feature of effective caregiver triads is open communication among all members. Therefore, our analysis focused on the decisions, actions, and interactions of the members of the triad in order to understand decisions to hospitalize. After reviewing all summaries, it became clear that the hospitalized cases fell into two distinct groups. One group was labeled “nonconflicted” admissions and the other group as “conflicted” admissions. Among the nonconflicted admissions, we found no evidence of disagreement about the admission decision among any of the coalition members. The physician ordered the hospital admission for either accidental injury or acute illness situations (usually respiratory infection), and there was no evidence of contradictory wishes by the residents, family, or other responsible parties. These admissions represented about 47% of the hospital cases (n = 9).

We were surprised to find that 55% (n = 5) of the residents experiencing nonconflicted admissions fit the palliative care definition at the time of hospital admission. Their reasons for admissions represented a mix of accidental and acute conditions, both of which could justify hospitalization. In addition, based on the dates at which each resident met the palliative care definition, and was hospitalized, we determined that most of these residents had recently segued to palliative care (6 months or less). These residents may still have been in blended care modes, a finding that offers preliminary validation for the inclusion of blended care in the schematic. The extent to which the long-term care environment may have had limits on the availability of certain types of care that might have been used to provide for adequate symptom
management in lieu of a hospital stay could not be determined from the chart reviews.

The remaining 53% \((n = 10)\) of the hospitalized cases included three distinct groups of conflicted cases, all of which stemmed from the actions or inactions of the individual members of the caregiver coalition. Eighty percent \((n = 8)\) of the conflicted cases were not in palliative care modes at the time of hospitalization, although all but one of the cases were in palliative care at the time of death. Ninety percent of the conflicted cases died within 6 months of their last hospital stay. Three scenarios summarize the conflicted cases.

In the first scenario, representing 30% \((n = 3)\) of the conflicted cases, the resident’s primary care physician was out of town or not on call when the resident’s condition became unstable and the decision to hospitalize had to be made. In the absence of explicit written instructions on the chart about hospital care or the general goals of care, the physician or physician’s assistant on call opted to send the resident to the hospital. Thus, the physician/LTC staff comprised the weak link at a critical decision-making juncture.

In the second scenario, consisting of 30% \((n = 3)\) of the conflicted cases, a nuclear family member (most often an adult child) was the resident’s responsible party. For reasons that were not apparent in the medical record, this person was not able to agree to or stay on a palliative care course, even when it was clear from the functional status of the resident that his or her condition was deteriorating. In each case, when the resident’s condition became unstable, the responsible party was unable to forgo aggressive curative care and opted for hospitalization.

The final set of conflicted cases \(40\%, n = 4\) was represented by a scenario in which the responsible party who held power of attorney was either not a family member (friend or attorney) or was a member of the extended family (niece or nephew). There was very little, if any, documentation in the medical record (social services and physician’s progress notes) about the resident’s wishes for care. Despite dire medical conditions, none of these residents met the palliative care operational definition because their responsible parties consistently chose to “do everything possible.” It was also the case that this group of residents appeared to be the most vulnerable for tumultuous end-of-life experiences. Two of these cases had multiple hospital stays the last year of life and two of the residents died without benefit of hospice care, family, or friends at their bedside. All of the residents in this subgroup died in the hospital or within one month of discharge.

**When Hospitalization Is Not the Choice**

Our analysis then turned to a review of the nonhospitalized residents’ case summaries. The most outstanding contrast between hospitalized and nonhospitalized residents was the documentation on the medical records clearly stating the wishes of the resident and/or the family for end-of-life care and hospital decisions. Letters were often found in the medical record from family members that stipulated “no transfer” orders. The care planning team documented the presence of family members at care planning conferences and their explicit wishes for no hospital care. Physicians’ notes tended to detail conversations with family members and the resident, when possible, about the course of care that would be followed, even for those residents who appeared to be in blended or transitional care. As might be expected, 81.8% of the nonhospitalized residents eventually died in hospice care compared to 58% of the hospitalized residents.

In summary, the hallmarks of care among the nonhospitalized cases were: open communication between all decision makers (family, physician, staff, and resident when possible); knowledge of the residents’ wishes by a responsible party; physician and staff commitment to following the wishes of the residents and families; explicit notes in the medical records about care decisions; and a commitment to stay the course of care. These findings were combined with the caregiving metaparadigm and prior research, especially the insights of Ackermann & Kemle (1999), to create the preliminary conceptual model for providing end-of-life care in LTC settings (see Figure 2).

The solid arrows in the middle of the Figure 2 represent the open communication that typifies the basic caregiver coalition in LTC. Ideally, all members of the coalition are active participants in the decision-making process. However, as our results demonstrated, there are certain tasks that are largely the responsibility of one member of the coalition and that most directly affect the behavior of another member of the coalition as the need for managing end-of-life care approaches. Therefore, while the center arrows represent simultaneous interaction among the triad members, the outside arrows and the associated call-out boxes are intended to represent directional patterns of responsibility for effective end-of-life care.

Recently, it was reported that nearly one half of nursing home transfers to hospitals may be inappropriate, based on interpretations by expert physician panels regarding the chief complaint on admission and the clinical care that was required in combination with the presence of an advance directive (Saliba et al., 2000). We believe that our present study and this earlier work may have also identified a subset of LTC residents whose hospitalizations may have been avoided. However, in our study we base that determination on a belief that one or more of the critical elements in Figure 2 may have been lacking. Further research on the appropriateness of nursing home transfers that combine clinical indicators (e.g., Saliba et al., 2000), location on the living–dying trajectory, and the responsibility assigned to each member of the triad in Figure 2 may improve our understanding of why some LTC residents are hospitalized and others in similar circumstances are not.

**Discussion**

As LTC residents move through living–dying intervals, the current standards by which their care is
evaluated have often resulted in murky decision making regarding such issues as aggressive acute care, transitions to palliative care, and the timing of hospice orders. A great deal of prior research has focused on clinical indicators to explain decisions to hospitalize LTC residents. As a result, authors frequently discuss the need for enhanced medical monitoring and supervision in LTC facilities. In large part these studies have ignored the need to identify residents’ placements on a living–dying trajectory, opting instead to apply active treatment standards and curative goals to the residents’ plans of care.

In this study we chose to search for implicit or explicit evidence that key decision makers and influential others had placed residents in palliative modes of care. We then examined their course of care in the last year of life from this perspective, searched for inconsistencies between the modes of care and subsequent hospitalization decisions, and sought to untangle some of the contextual variables that supported or interfered with care decisions and the provision of end-of-life care.

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Recently, the issuing of DNR orders 24 hours or more after hospital admission has been called “medical last rites” (DeJonge, Sulmasy, & Gold, 1999). Hospitalization may represent a similar message of futility and finality to families of LTC residents who are known to have tendencies toward delaying end-of-life discussions and agreement on appropriate care (Happ et al., 1999; Wilson & Daley, 1999). Unfortunately, when hospitalization is the trigger event for end-of-life care planning, little time is left for appropriate end-of-life preparation and palliative care.

From these results it is apparent that many LTC residents need more clearly defined palliative plans in advance of the need to decide about hospital care. If, as we have suggested, hospitalization and subsequent orders for hospice care fit the concept of medical last rites, then one needed change is to find better ways of helping families understand the futility of treatment and to recognize a need for a shift to palliative goals of care. To this end, the model in Figure 2 is offered as a springboard for additional research on effective programs of end-of-life care. As research programs continue to mature, it is likely that other elements will be added and that cause-and-effect relationships will be clarified. For example, the influence of prevailing public policy and related reimbursement issues pertaining to end-of-life care in LTC settings (Petriske & Mor, 1999) were not immediately apparent in the present study of private-pay, life-care retirement community residents of high socioeconomic circumstances. Both the generalizability of the study results and the applicability of the model across long-term care populations are affected by our small sample size and the study setting.

We close with acknowledgment of our rather crude operational definition of palliative care and a
call for greater attention to ways in which clinicians and researchers can measure this important concept of care. Prognosticating an individual’s ability to survive 6 months or less for purposes of implementing a hospice plan is widely recognized as a very difficult task. But until diagnosticians are able and willing to make these determinations, other members of the care planning teams, family members, and the care recipients will invariably struggle to find direction and make informed decisions about end-of-life care. A significant area for future research will be better delineation of inevitable transitions in care among residents in LTC and the role of palliation treatment goals and hospice care during the final transition to death.

References


Correction

In an article on retirement preparedness that appeared in the December 2000 issue (vol. 40, no. 6), Hershey and Mowen reported a series of correlations in Table 1 (page 692). Due to a transcription error by the authors, incorrect valences were reported for 14 of the values contained in that table. The actual valences for all values in column three and row three of the table (involving the variable “emotional stability”) should be reversed; positive values are actually negative, and negative values are actually positive. This error did not affect either the structural modeling analyses the authors describe, nor the conclusions they draw in the text.