

# Meaning and Practice of Palliative Care for Nursing Home Residents With Dementia at End of Life

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*Objective:* To describe the meaning and practice of palliative care (PC) for nursing home (NH) residents with dementia at end of life (EOL). *Design:* Concurrent mixed methods (quantitative retrospective chart review and qualitative field study). *Setting:* Three NHs with varying approaches to EOL care: in-house non-Medicare hospice, Medicare hospice by outside agency, and Medicare hospice by outside agency plus specialized staff and comfort care unit. *Results:* Residents' course fluctuated between curative and comfort care, with a noticeable increase in symptoms right before death.

Hospice care was short. Most died of complications of dementia. Families found care decisions based on residents' uncertain disease course difficult. *Conclusion:* The role of PC for NH residents with dementia at EOL is complex and poorly understood. As they are in a residential setting, decisions need to be made about how residents live, as well as how they die, thus balancing quality of living/comfort with disease management.

**Keywords:** dementia; palliative care; end of life; nursing homes

A majority of older Americans with dementia as the underlying cause of death (66.9%) die in nursing homes (NHs).<sup>1</sup> NHs currently are better suited than acute care environments to meet their long-term needs by providing not only nursing and medical care but also a living space.<sup>2</sup> Because they are residential, the demand to balance quality of living/comfort and management of the disease and its complications is unique to NHs, as entities within the health care system. Yet the quality of end-of-life (EOL) care in these facilities is an ongoing source of consumer dissatisfaction and professional caregiver concerns.<sup>2-6</sup> Furthermore, there is neither a precise definition of the interval referred to as

EOL<sup>7</sup> nor a single definition of palliative care<sup>8</sup> (PC). This definitional ambiguity plays a role in our report of research that at its inception posed the overarching question, "Should EOL care begin sooner for NH residents with dementia?" Based on our clinical experience in NHs that suggested presence of PC needs prior to designation of care as palliative once persons were perceived to be approaching EOL, the research focused on what the last year of life was like for NH residents with dementia. The findings broadened our own understanding of the historical definitional evolution underpinning the philosophy of PC<sup>8,9</sup> at the same time that they revealed what happens as a result of health care provider and lay public perceptions of its meaning. Perceptions, then, are compounded with their experiencing of the unforgiving relentlessness of dementia-related diseases characterized by long courses (some persons living up to 20 years after diagnosis) and uncertain illness trajectories<sup>10</sup> (prognostic indicators of when life will end being less pronounced than for other diseases). The unique contribution of this research is the manner in which it connects actual EOL needs of persons with dementia to the complexities of PC in residential NH settings.

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## Methods

A concurrent mixed methods design<sup>11</sup> was used involving 2 independent strands, one quantitative (QUAN) and the other qualitative (QUAL), each with its own set of questions, independent samples, and method-specific sampling, data collection, and analysis techniques. The QUAN strand (a retrospective chart review) addressed questions about (a) symptoms and complications experienced, (b) interventions provided (comfort vs curative), (c) decisions to limit curative care (do not hospitalize, use of hospice/comfort care), and (d) cause and location of death for NH residents with dementia during their last year of life. The QUAL strand (an ethnographic field study) examined resident, family, and staff member points of view about what was good/not good and what could be done differently with regard to the EOL experience in terms of (a) managing symptoms, (b) assessing and treating discomfort/pain, and (c) monitoring the physical/social environment. Results from both data analyses were integrated at the end of the study as meta-inferences. For clarity of reporting, each strand will be presented separately prior to this concluding integration of analytic inferences.

### Setting

The study was conducted in 3 nonprofit urban NHs in upstate New York with varying delivery approaches to PC at the EOL: in-house non-Medicare hospice, Medicare hospice by an outside agency, and Medicare hospice by an outside agency plus specialized in-house comfort care staff and a designated comfort care unit. Bed size ranged from 150 to 500. NHs were selected because of their variation in approaches and high quality of care. The latter was based on their favorable annual state/federal surveys compared with other regional NHs.

## The Quantitative Study Strand Methods

### Quantitative Subjects

This was a random sample chosen over a 1-year period. Residents who met the study criteria (ie, a diagnosis of dementia based on medical documentation and residence in the NH at least 1 year prior to death) were randomly selected (1 from each NH

each month) until a sample of 30 was obtained. Cases were distributed evenly across the 3 NHs.

### Quantitative Procedure

A retrospective chart review was conducted for the entire 365 days preceding death regarding (a) the symptoms/complications of dementia experienced, when they occurred, and how they related to the resident being designated as terminal/hospice/comfort care; (b) interventions used in relation to possible treatment options, level/aggressiveness of intervention, shifts and progressions of interventions toward aggressive versus more comfort/symptom relief approaches, indications of the beginning of a palliative EOL plan of care, location of death, and cause of death; (c) factors that may influence the pattern of EOL care, such as resident characteristics/stage of dementia, advance directives, and location of care—dementia special care/comfort care/general unit or hospital.

Because these data were drawn from documentation (notes, medical orders, tests, examinations, histories, treatments, and minimum data set forms), chart review was deemed a reliable method for collection of this type of information. Also, extensive training was provided to highly experienced nurse data collectors to verify interrater reliability of symptoms, with ks ranging from .72 to .89. Although underreporting of symptoms, based on documentation, may have occurred, variation over time was believed to be unlikely. Interventions were classified by the investigators according to their aggressiveness (curative vs comfort/symptom control). Face validity was verified by 4 NH clinicians with expertise in PC (a geriatrician, 2 advanced practice nurses, and a comfort care unit nurse manager). Location and underlying cause of death were determined from charts or other facility documentation.

### Quantitative Analytic Plan

Descriptive statistics were used to portray the nature of needs and treatments experienced by NH residents with dementia during their last year of life.

## Quantitative Results

### Characteristics of the Sample

Most were female (21/30, 70%), white (29/30, 98%), and older at the time of death (mean/median = 87,

with an age range of 74-100 years). Length of stay in the NH ranged from 1 to 10 years (mean = 3.3; median = 2.4). At death, cognitive impairment as measured by the Cognitive Performance Scale<sup>12</sup> was at the "very severe level 6" for 60% (mean = 5.1; median = 6).

### Characteristics of Death

The majority (73%) died of complications of dementia, such as poor nutritional intake, pneumonia, bronchitis, and/or urosepsis. Other causes of death (40%) were cerebrovascular accident, myocardial infarction, cancer, renal failure, abdominal perforation, and peritonitis based on chart and/or other facility documentation. More than 1 cause of death was possible for each case. Most residents (60%) were at the end stage of dementia at time of death, as indicated by very severe cognitive impairment. All (100%) died in the NH, including a few (20%) who died in a special dementia care unit.

### Life Prolonging Intervention

Despite a lack of universal advance directives against extraordinary life prolonging measures (cardiopulmonary resuscitation, mechanical ventilation, feeding tubes), no resident received them during the last year of life. Wishes regarding hospitalization were less consistent, with fewer than half (43%) designated as do not hospitalize (DNH) at the start of 12 months, and did not change much until the last 2 months of life (ie, 60% at 2 months prior to death and 83% in the last month). Nevertheless, there was only sporadic use of emergency rooms (9 short-term visits) and hospitals (4 stays in non-intensive care units for management of infections [3/4] and a deep vein thrombosis [1/4]).

### Symptom Management

Although life-prolonging care was rare, management of symptoms was less conservative. Over the last year, there was no clear progression from more aggressive treatment to comfort and/or symptom relief. Shifts in aggressiveness fluctuated between curative and comfort/control of symptoms. Examples for poor nutrition/difficult swallowing/refusal to eat include dietary supplements, encouragement of food and fluids, and intravenous hydration versus thickened liquids; aspiration precautions; and nourishment as

tolerated. Examples for weakness/debilitation include reconditioning and exercise versus low activity level, bed rest, and oxygen. Examples for fever and pain include surgery for underlying causes of infection versus bed rest and symptomatic relief. Most residents were not designated terminal (3%), comfort care (23%), or hospice care (3%) at the start of 12 months. Changes in designations did not consistently occur until the last 2 months, but use of Medicare hospice when available fluctuated throughout the 12 months, with residents going on and off. During the last month of life, 40% were designated as hospice care and two thirds were comfort care.

### Symptom Occurrence

However, most symptoms related to dementia and comorbidities were present at the beginning of the last year of life with the exception of septicemia and contractures, which were not present until the last month of life. About half of the symptoms were present in a relatively stable number of residents throughout the entire 12 months prior to death (ie, gait disturbances, fractures, edema, localized pain, urinary tract infections, depression, anxiety, withdrawal from socialization, seizures, and deep vein thrombosis). A few symptoms gradually increased in prevalence over the 12 months (ie, difficulty in swallowing/refusal to eat and agitation). The remainder increased primarily at the EOL (ie, weakness/fatigue, constipation, fever, generalized pain, breathlessness, nausea/vomiting, pneumonia, skin breakdown, septicemia, decreased awareness, and severe contractures). Of note, although symptoms were present throughout the year preceding death, the number of symptoms jumped dramatically from an average of 5.23 to 9.34 symptoms in the last month of life. This phenomenon did not occur in any other month and may partially explain why the greatest number of residents (40%) used hospice care (with a median duration of only 14 days) during their last month of life.

## The Qualitative Study Strand Methods

### Qualitative Subjects

The unit of analysis was the individual resident case (n = 30), which included the resident, family members, and NH staff. Cases were selected purposefully

over a 3-year period to form a database composed of persons with a terminal prognosis and moderately severe to severe dementia based on their Cognitive Performance Scale<sup>12</sup> impairment level with comorbidities that, in most instances (25/30), resulted in hospice referrals or comfort care placement. Cases were distributed evenly across the 3 NHs.

### Qualitative Procedures

Using an iterative process of simultaneous data collection and analysis, observations and interviews were performed by the investigator (BP), who is an anthropologist and field researcher, and a project nurse with extensive field experience in prior NH studies. Data based on observations in the NH settings were recorded in field notes; interview guides were used in taped and transcribed formal interviews. Content analysis was used to identify themes and patterns in the data through a process of coding and clustering data bits into informational categories, writing analytic notes about the ability of emerging findings to address study aims, and developing interpretations of what the findings signify based on the empirical evidence. Data were coded and clustered in accordance with perceptions and observations about what was seen as (a) “good” or “effective” management of resident/family needs and (b) “challenges” in terms of “what could have been done differently.” Categories reflecting resident/family/staff perceptions of good and/or effective and challenging aspects of their experiences were (a) views of the EOL care experience in general, (b) experience with the symptoms/complications of dementia, (c) experience with physical and/or emotional discomfort, and (d) views of the nursing home care environment. Adequacy of the database, to maximize diversity, was ensured by continuous analysis that guided data collection via purposeful sampling. The themes described below were identified by synthesizing common across-category patterns, built on the researcher’s frame of reference concerning the research aims and observations, interpretations, and meaning inherent in the data.

### Qualitative Results

#### Characteristics of the Sample

Most (25/30, 83%) were female. They ranged in age from 75 to 100 years. Symptoms experienced by this

sample were not unlike those experienced by subjects in the quantitative sample. Only 6 out of the 30 residents were able to sustain limited conversation, the majority being either too ill or unable to communicate in words.

#### EOL Program Use

The majority (25/30, 83%) used hospice or comfort care when enrolled (16/30) or at some other point during participation in the study (9/30). However, enrollment in Medicare hospice was inconsistently maintained by some, who improved to a degree where they no longer met eligibility criteria (terminal prognosis of 6 months or less). This phenomenon also occurred in the NH with only an in-house program (no Medicare hospice), although that model focused attention on residents expected to be weeks from death. A staff member explained, “We have found that often, with extra care and attention, they get better. And after they’ve been on the program for several months, we’ll very likely take them off and wait for another time.”

In contrast, the NH with a comfort care unit and specialized in-house staff often accepted residents for that unit who might have a prognosis of a year or longer. A nurse provided the following explanation.

So we have some that are really palliative care. They need to have a DNR, a DNH, and to want a basic palliative care approach. The reason we’re not a hospice unit is because of the hospice guidelines where you have to meet certain criteria and die within a certain timeframe . . . But we also take Comfort Care throughout the Home . . . [So] residents who choose to age in place with Comfort Care will stay on their long-term unit and we’ll call Hospice [agency] and make a referral.

Ten participants out of 15 who died (50%) while enrolled in the study were in a hospice program or on the comfort care unit for a median length of 21 days.

#### Themes: Gauging Decline and Intervening Appropriately

“Gauging decline” (difficulty in predicting prognosis) and “intervening appropriately” (symptom management challenges) were 2 of the 4 themes derived. Though dementia syndromes are progressive and eventually fatal, the course that individual cases follow

is not easily predictable. This affected communication when either caregiver or family members waited to address EOL issues until death seemed imminent or, at least, more certain. What the experience feels like when caregivers postpone these discussions, is captured in the following.

[Family member]: The one thing I would like to know from the doctor is—“How is she . . . really? . . . What do you think?” Because sometimes I think she isn’t going to last another 2 weeks, or even 1 week. And other times I’ve come up . . . and it’s just like she’s suspended in that one spot . . . like it’s going to go on forever. But, of course, I know it’s not. I’d just like to know how she is [prognosis] in the physician’s opinion. It’s not that I’m in a hurry. That’s not it. But, you know . . . I want to be prepared.

In contrast, when staff encouraged consideration of hospice, some families found it difficult to face EOL issues. For example,

[The cancer’s] spreading and [she can’t be] put through any more chemotherapy [or] surgery. They want to put her on hospice care. [But] she’s been on hospice before and she came right out of it. We don’t see her on a decline toward death.

Uncertainty also caused some families to, in one staff member’s words, “hold onto that . . . ‘hospitalize if necessary’ treatment preference” beyond, what they discovered through hard experience, was a need to shift to a more comfort oriented approach. “We finally got her back [from the hospital],” one family member said, describing the workup for unidentified bleeding source. “All the trauma of that episode, emotionally, wasn’t worth it. So this is when we went over palliative care as I think I understand it here.”

Emotional discomfort was experienced by a majority (70%) of residents who, in response, received psychotropic medication for depression, anxiety, and/or agitation. Also, all 30 residents (100%) suffered varying degrees of physical discomfort. Many had chronic pain and received analgesics on a routine basis because of cognitive or language impairments that left them unable to verbalize distress or request relief. “Usually she says she’s ‘fine’ even when you don’t think she’s fine,” a family member said. “So she gets Tylenol around the clock.” However, severe and progressive pain was less well managed for residents who were not residing on the specialized comfort care unit or covered by Medicare hospice.

## Themes: Maintaining Normalcy and Upholding Dignity

Maintaining normalcy (consistency of everyday life) and upholding dignity (respect and human love) were the other themes derived from the qualitative data set. Families preferred aging in place within the NH (continuity of care/familiar staff and surroundings) but found availability of staff to be less than desired as amount of time required to assist end-stage dementia residents (particularly those with eating difficulties and decreased mobility) intensified. They appreciated attempts at creating a homelike environment and expressions of caring and affection from staff members, who for some were “like extended family.” But some family members registered distress if residents were not included in activities/social events because staff thought they would not benefit. Most salient, in terms of overall satisfaction with care, was the reality of usual NH staffing patterns that limit amount of time that staff can allot to individual residents. Thus, the Medicare hospice benefit boosted the bottom line by providing recipients of this care with extra hours of dedicated one-on-one attention, which was seen to make a positive difference though even that was viewed, at times, as insufficient.

## Discussion

Sampling strategies in mixed methods (MM) studies stem logically from and generate databases addressing the research questions under investigation in each strand. “Combining the two orientations allows the MM researcher to generate complementary databases that include information that has both depth and breadth regarding the phenomenon under study.”<sup>13(p85)</sup> The following conclusions regarding the meaning and practice of PC in NHs for residents with dementia at the EOL were derived from integration of analyses from both the quantitative and qualitative research findings.

Persons living in NHs because of dementia, to all intents and purposes, are most likely to be approaching the end of their lives. But, in the absence of adequate markers of terminal status,<sup>10,14</sup> the question is not “When will they die?” but “How shall they live?” On the one hand, the terminality of NH residents in advancing stages of dementia is often denied despite tacit understandings about the progressive nature of the disease and its inevitable clinical outcome. But inadequately addressed unknowns/uncertainties

about what an individual's dying trajectory will be give rise to family members' fears and doubts, as described. On the other hand, what is not addressed directly may be enacted ritually by increasingly excluding residents from the social worlds in which they live if they cannot provide cues that others look for to determine their awareness of what goes on around them. These examples suggest a need to begin communication about PC principles as early as possible to provide information and sustain a focus on quality of life consistent with resident–family goals and values over the course of what can be a slow and relatively long dying process in an NH.

Symptom-specific palliative and disease-specific curative modalities may be used simultaneously to promote comfort and maximize quality of life. Treatment needs of persons with dementia are diverse, complex, and lacking in uniformity. As findings demonstrate, transitions from one level of treatment to another across the EOL experience may be neither clear-cut nor absolute. Thus, the use of “palliative care” as an antonym for “curative care” creates a false dichotomy that undercuts the notion of comprehensive care. This may also explain family members' resistance to an approach suggestive of loss and limitation of treatment options. This confusion is compounded when talk of a PC approach is coupled with the anticipation that death is near. The sense of “giving up” that families derive from this juxtaposition needs to be replaced by early and ongoing honest conversations with providers regarding residents' EOL options and realities, which send a different message of the goal of “staying the course.”

Palliative care is a holistic approach that focuses on relieving suffering and enhancing quality of life by coordinating provider efforts and tailoring care plans to patient–family goals and values. Organized PC programs use an array of delivery systems (eg, consultation, special care units) that are open to all seriously ill persons regardless of prognosis. In contrast, hospice is a care delivery system oriented toward comfort care of the dying. The similar holistic philosophies of “hospice” and “palliative care” often obscure their key differences. Data from both study strands reflect the use of “palliative care” as a synonym for “comfort care” and “hospice.” Moreover, evidence showed that staff tended to define it narrowly in terms of treatment aimed at relief of pain and avoidance of invasive life-prolonging procedures, even though PC is not just about medical regimens. To satisfy its other dimensions—psychosocial and emotional/ spiritual

needs of residents and families—hospice was often used to augment the insufficient amount of time staff could contribute. Findings that residents improved on hospice programs (to a point where they were no longer eligible to receive services) illustrate the palliative effect of social stimulation and emotional support. However, residents receiving it for limited amounts of time and/or rotating on and off the program minimized hospice's effectiveness. It has been suggested that the capacity of PC in NHs could be expanded by changes in hospice contractual rules to address this type of underutilization.<sup>15</sup>

In theory, PC encompasses what the usual care of NH residents with dementia should be from time of admission. Thus, in practice, it should not be introduced as an alternative approach to care when persons are in a precipitous decline from which they are not expected to recover. The findings suggest that the timing and interpretation of PC in NHs may be at cross-purposes with the actual EOL needs of residents with dementia and their families. These EOL needs—to understand the condition and the treatment options, to adjust to changes over time, to live fully while preparing for the dying process and death—need to begin and be ongoing from time of diagnosis.

Despite the limitations of the quantitative sample size and selection of high-quality NHs, it seems fair to conclude, based on these findings, that NHs are, or could be, appropriate residential settings for a PC approach for residents with dementia. However, confusion exists in its meaning to families and staff. PC strategies should be a part of all care provided to this NH population regardless of disease stage to maximize the lives of residents and families. EOL care also needs to be improved through more adequate and flexible staffing ratios, better pain management, in-house geriatricians and nurse practitioners to avoid unnecessary hospitalizations, and a willingness to allow residents to die on their own terms in the NH space that has been their home.

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