Original Article

Quality of Life at the End of Life for Nursing Home Residents: Perceptions of Hospice and Nursing Home Staff Members

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Abstract
This study examined whether the perceptions of nursing staff members about the importance of quality-of-life domains and their perceived ability to influence those domains for residents at the end of life were affected by their institutional affiliation, level of training, or residents’ cognitive status. Respondents were 146 Certified Nursing Assistants (CNAs) and Registered Nurses (RNs) from nursing homes and hospices. Magnitude estimation scales were used to rate the importance of and perceived ability to influence 11 quality-of-life domains for both cognitively intact and cognitively impaired residents. Overall, respondents’ scores indicated a high level of importance of all quality-of-life domains and similarly positive perceptions that they could influence quality-of-life domains for hypothetical nursing home residents. Analysis of variance revealed that respondents reported lower average importance and ability to influence ratings when considering residents with cognitive impairment. Respondents affiliated with hospice agencies also reported lower average importance and ability to influence ratings on some domains, although the high ratings overall limit the clinical significance of these differences. Importance ratings were not affected by the level of education, but CNAs reported higher perceived ability to influence ratings on four domains than did RNs. Future studies should explore whether the domains measured adequately capture the end-of-life experience in nursing homes. J Pain Symptom Manage 2008;35:1–9. © 2008 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words
Psychosocial assessment, quality of life, end of life, nursing homes, nurses, hospice

Introduction
Identifying and validating quality-of-life domains appropriate for the long-term care environment have become an increasingly important policy and research goal. In response to criticism that nursing homes emphasize promoting health and safety may be accompanied by relatively low expectations for residents’ quality of life, the Centers for Medicare and Medicaid Services (CMS) launched two 2006 initiatives to improve quality of life for nursing
home residents. Effective from June 1, 2006, surveyors implemented a set of standards for evaluating psychosocial harm among nursing home residents. Beginning in July 2006, the Minimum Data Set (MDS 3.0) revised standards were tested to include the requirements that quality-of-life resident interviews be validated and evaluated. Both of these initiatives signal that resident quality of life should be emphasized in care planning.

While laudable, these efforts seem to assume that quality-of-life nursing home domains apply equally to all residents, both to those admitted for shorter-term, postacute rehabilitation and those with chronic care needs, who may reside in the nursing home until they die. Furthermore, the pressure to create a summary score for quality of life to meet CMS requirements may obfuscate shifts in domain importance as residents’ desire for aggressive care changes. Indeed, the pressure for a summary score has the potential to oversimplify the inherent value of a subjective quality-of-life scale and the importance of various quality-of-life domains, especially as residents approach the end of their lives.

Quality of life near the end of life in nursing homes remains relatively unexplored. Recent demographic trends make it of particular importance to examine quality of life at the end of life for residents of nursing homes. Nearly one in five older adults will die in a nursing home, with many more dying in a hospital after becoming institutionalized, still others are transferred to nursing homes from hospitals in the last weeks or days of life.

While quality of life in nursing homes and other highly regulated medical institutions typically emphasizes the avoidance of negative outcomes, there is increasing recognition of the importance of including the pursuit of pleasurable outcomes also. Physical comfort and freedom from physical pain and other discomforts are a prerequisite of quality of life. Autonomy, privacy, dignity, and individuality are highly dependent on cognitive abilities; however, quality of life is enhanced when each person is treated with dignity regardless of whether he or she can perceive indignities, whether people are allowed to make choices within their abilities, and to what extent their wishes are known and honored when they can no longer communicate them effectively.

Functional competence relates to the ability to be as independent as one desires within one’s capabilities, and its importance may differ between nursing home staff members who are trained to emphasize rehabilitation, and hospice staff who expect functional decline near life’s end. Meaningful activities and relationships, whether with staff and/or family are key elements, although the activities that are valued and hold meaning for residents may change as life comes to a close. The ability to enjoy food is also an important component of residents’ quality of life; again, we note that a resident’s experience with food may change and its importance may decrease as death approaches. Personal safety, security, and trust that one’s living environment is benign and that people are well intended is a foundation of quality of life. Spiritual well-being, though elusive and related to both psychological and social well-being, is a distinct construct that can incorporate and also go beyond the concept of religiosity, especially for residents with cognitive impairment.

This study extends a methodology for examining staff attitudes about the quality of life of nursing home residents to the end-of-life context. Results of a recent multisite collaborative study that asked participants to rate the importance of quality-of-life domains and their ability to influence those domains for hypothetical nursing home residents revealed that there were statistically significant differences in mean ratings for categories of residents and among paid care providers. Ratings for hypothetical residents with cognitive impairment were consistently lower. Ratings from Registered Nurses (RNs) and Certified Nursing Assistants (CNAs) were generally higher than others and physicians’ ratings were generally lower. The purpose of the present study was to investigate which quality-of-life domains nursing staff in nursing homes believe are important for resident quality of life near the end of life, and to measure their perceptions of their ability to influence those domains.

The present study used the quality-of-life domains and magnitude estimation methodology validated in the multisite study, but asked respondents specifically about the importance of these domains for hypothetical nursing home residents near the end of life. In addition, respondents were asked to rate their
perceived ability to influence quality-of-life domains for residents at the end of life. Importance and ability to influence ratings were compared to those of hospice nursing staff members caring for nursing home residents, who bring specialized clinical knowledge and skills in palliative and end-of-life care to the long-term care environment.

Our hypotheses reflect what was observed in the multisite study,\textsuperscript{6,11} that is, there is an inverse relationship between level of medical education/training and ratings of the perceived importance of quality-of-life domains, and one’s perceived ability to influence these domains. Also consistent with the multisite study, we predicted that since residents with end-stage cognitive impairment pose additional challenges to staff, respondents would report lower importance and ability to influence ratings for these residents than for cognitively intact residents with life-limiting physical impairments. In the study reported here, we examined whether these relationships are maintained in the special context of end of life, where there is growing evidence that quality of care and satisfaction with care is improved when care is provided by hospice staff with specialized skills in palliative and end-of-life care.\textsuperscript{12}

Methods

A sample of nursing staff from Florida nursing homes (50 RNs and 50 CNAs) and a comparison group of hospice nursing staff caring for nursing home residents (24 RNs and 22 CNAs) participated in the study for a total sample of 146 respondents. Respondents who were RNs were recruited at the annual statewide conference for long-term care providers. Paraprofessional staff members were recruited with the assistance of the Director of Nursing from a large not-for-profit nursing home in the Tampa Bay area. Hospice staff members were recruited from a large not-for-profit hospice in the Tampa Bay area with a significant presence in nursing homes, and at meetings of hospice paraprofessionals. University of South Florida Institutional Review Board approval was granted for the study, and informed consent was obtained from all respondents.

Participants completed questionnaires during breaks between conference sessions at the statewide meeting or between nursing home shifts. Respondents were told that their participation was voluntary and not a requirement of their job responsibilities, and that their responses would be kept confidential. Respondents received a small stipend for completing the survey, which took approximately 30 minutes to complete. The authors provided a brief introduction to the magnitude estimation scales and hypothetical nursing home resident descriptions, and were available to answer questions as needed during survey administration.

This study used the domains identified for measuring quality of life in nursing homes\textsuperscript{1,2,6} and the magnitude estimation methodology used in the multisite study described previously.\textsuperscript{6,11} Respondents rated the importance of and perceived ability to influence 11 quality-of-life domains: freedom from pain, autonomy, privacy, dignity, individuality, functional competency, meaningful activities, food enjoyment, meaningful relationships, personal safety, and spiritual well-being.\textsuperscript{1,2,6,10}

Respondents rated the importance of and their perceived ability to influence each of the quality-of-life domains using a 10-point magnitude estimation scale, where 1 = not important at all (or no ability to influence) and 10 = very important (or great ability to influence). Each domain was described in a sentence format, for example, “They are free from pain and they do not have uncomfortable
problems or other physical discomforts” represented the domain “freedom from pain.” Respondents were asked about two hypothetical residents: those who were cognitively impaired but physically intact, and those who were cognitively intact but physically impaired, both of whom were near the end of their lives.

Analysis of variance using the General Linear Model in the Statistical Package for the Social Sciences (SPSS version 13.0 for Windows) was used to analyze the data. Institutional affiliation (hospice, nursing home) and level of education/training (RN, CNA) were between-subjects factors and resident type (cognitively impaired, physically impaired) was a within-subjects factor. Ratings for importance and perceived ability to influence each of the 11 quality-of-life domains were analyzed individually, as the goal of the present study was to examine the perceptions of nursing home and hospice staff members about specific quality-of-life domains relevant to end-of-life care, rather than to compare overall measures of quality of life, which can mask important nuances.

**Results**

**Participant Demographics**

The majority of survey respondents were female (97%), with an average job tenure of 5.3 years. RNs and paraprofessional hospice staff members were predominantly White (86% of nursing home RNs, 100% of hospice RNs, and 90% of hospice paraprofessionals). CNAs in nursing homes reported their race/ethnicity as 27% White, 33% African American, 25% Hispanic, and 15% other.

**Importance of Quality-of-Life Domains**

Contrary to our hypothesis, no significant main effects for level of education/training on importance ratings of any of the quality-of-life domains were found. Average ratings by CNAs were not significantly higher than ratings by RNs; all respondents rated quality-of-life domains as highly important, and there was limited variability in the ratings. RN ratings ranged from a low of 8.520 for enjoyment of food to the highest rating of 9.530 for freedom from pain. CNA ratings ranged from a low of 8.806 for individuality to the highest rating of 9.371 for privacy.

Average ratings by hospice staff members were lower than average ratings provided by nursing home staff members at all nursing levels, contrary to our hypothesis that the specialized knowledge of hospice staff would result in higher importance ratings on quality-of-life domains. Average ratings provided by staff members associated with hospices on the importance of autonomy, privacy, dignity, functional competence, meaningful activities, food enjoyment, individuality, meaningful relationships, and spiritual well-being were lower than average ratings provided by nursing home staff members. Ratings of the importance of personal safety and pain management were not affected by staff members’ institutional affiliation.

As predicted, cognitive impairment in hypothetical nursing home residents near the end-of-life significantly and consistently lowered respondents’ average ratings of the importance of quality-of-life domains. Significant main effects for resident type were revealed for autonomy, privacy, dignity, functional competence, meaningful activities, individuality, meaningful relationships, personal safety, and spiritual well-being. These findings were mostly consistent with our hypothesis that the presence of cognitive impairment in residents would lower staff ratings of the importance of quality-of-life domains, although ratings of the importance of pain management and ability to enjoy food were not affected. Means, standard errors, and significance values are reported in Table 1.

Significant interaction effects were revealed between resident type × level of education/training such that RNs’ importance ratings for cognitively impaired residents were lower than CNAs’ ratings on the importance of privacy, F(1,138) = 5.358, P = 0.022; dignity, F(1,132) = 5.158, P = 0.025; and spiritual well-being, F(1,141) = 5.544, P = 0.020. Significant interaction effects were revealed between resident type × institutional affiliation such that hospice staff importance ratings for cognitively impaired residents were lower than nursing home staff ratings on autonomy, F(1,141) = 4.350, P = 0.039 and dignity, F(1,132) = 4.134, P = 0.044.

**Ability to Influence Quality-of-Life Domains**

Level of education/training significantly impacted average ability to influence ratings such
that CNAs perceived greater ability to influence some quality-of-life domains than did RNs, which partially supported our hypothesis. Significant main effects for level of education/training on ability to influence ratings were revealed for the following quality-of-life domains: autonomy, privacy, dignity, and food enjoyment.

Average ratings by hospice staff members at all nursing levels were lower than nursing home staff members’ average ratings of their ability to influence most quality-of-life domains, contrary to our hypothesis. Significant main effects for institutional affiliation were revealed for autonomy, privacy, dignity, functional competence, meaningful activities, food enjoyment, individuality, meaningful relationships, and personal safety. Hospice staff members reported ratings comparable to those of nursing home staff members on ability to influence pain management and spiritual well-being, which are particular hospice competencies.

Cognitive impairment in hypothetical nursing home residents near the end of life significantly and consistently lowered ratings of the perceived ability to influence quality-of-life domains. These findings were consistent with our hypothesis that nursing staff members perceive that they are less able to influence quality-of-life domains for nursing home residents with cognitive impairment who are near the end of life. Significant main effects for resident type were revealed for all quality-of-life domains measured. Means, standard errors, and significance levels are reported in Table 2.

A significant interaction effect was revealed between resident type × institutional affiliation such that hospice staff ability to influence ratings for cognitively impaired residents were lower than nursing home staff ratings on autonomy, $F(1,138) = 8.170, P = 0.005$.

**Discussion**

Our findings in the end-of-life context partially supported the findings of prior studies, particularly the multisite study on which the present study is based. Advanced nursing training lowered the average ability to influence ratings, but not ratings of importance, so our hypothesis about the influence of level of education/training was only partially supported. Hospice staff members reported lower average
importance and ability to influence ratings than did nursing home staff members, although hospice staff members’ perceived ability to influence pain management and spiritual well-being, which are particular hospice competencies, were comparable to ratings by nursing home staff members. Respondents’ average ratings of the importance of quality-of-life domains and their perceived ability to influence them were higher when considering physically impaired rather than cognitively impaired residents. Overall, however, respondents’ average ratings of the importance of quality-of-life domains and their perceived ability to influence these domains were more similar than different. Some patterns revealed in this study may be worthy of future investigation, and there are several implications of these findings.

These results highlight the critical role that CNAs and paraprofessional hospice staff may play in the quality of life of nursing home residents near the end of life. CNAs and hospice paraprofessional staff in this study reported the highest average ratings of the importance of quality-of-life domains for all nursing home residents near the end of life, and the highest average ratings of perceived ability to influence residents’ quality of life. CNAs provide much of the hands-on care that residents receive, and the results of this study show that these staff members believe that they can be influential in affecting the quality of life of nursing home residents in their care. Quality of life for nursing home residents is a function of how they are treated; thus, care providers’ attitudes about quality of life are critical.15–19 These positive beliefs combined with specialized training in palliative and end-of-life care and mentoring by hospice nurses, especially for nursing home CNAs, might help translate these positive perceptions into even more meaningful improvements in the quality of care that dying nursing home residents receive on a day-to-day basis.

Although hospice staff members’ ratings were lower than those of nursing home staff, all ratings were high, and there was more similarity than difference among respondent groups. All respondents, regardless of institutional affiliation, reported high average ratings of the importance of quality-of-life domains and of their ability to influence such domains. It is
important to note that the statistical significance may not equate with clinical significance. For example, average ratings of the importance of privacy between hospice staff members and nursing home staff members were 8.718 and 9.640, respectively. If instead of measuring the perceived importance of this domain, one was evaluating pain management outcomes using the average level of pain, an average of 9.64 and an average of 8.718 would both represent severe pain. The statistical significance of a reduction of pain from an average score of 9.64 to 8.718 (assuming similar sample sizes) would not be clinically relevant, and one would conclude from these two outcomes that no clinical impact on pain control was achieved for that population. Thus, the statistically significant differences reported here should be approached with suitable caution.

The differences noted, however, may identify potential issues that should receive further attention, especially during the validation of new MDS standards for nursing homes. The differences identified in this study suggest potentially interesting future studies that can parse out the relative contributions of specialized knowledge/skills and professional roles in perceptions about residents’ quality of life and one’s perceived ability to influence it. For example, these findings may suggest that hospice nursing staff members place different weights on quality-of-life domains for nursing home residents at the end of life, perhaps valuing comfort and spiritual well-being and placing less emphasis on security, food, and other domains. There is a potential clash of values and cultures between nursing home staff and hospice staff on the relative importance of various quality-of-life domains at the end of life. Especially in contrast to the home environment in which much of hospice care is provided, the nursing home environment is both confining and highly regimented, which may also affect hospice staff members’ perceived ability to influence residents’ quality of life. For example, hospice staff members tend to emphasize individual choice, and may be willing to defer to residents’ food preferences; nursing home staff members are aware of the “red flag” that unintended weight loss in residents triggers, and awareness of this institutional reality may influence their patterns of care. Hospice staff members working in nursing homes may need reminders of these institutional norms in nursing homes, and nursing home staff members may need reminders of the benefits to all residents when hospice is present in the nursing home. Studies have documented that increasing access to hospice services for nursing home residents improves the quality of the end-of-life care they receive, and may elevate the level of care for other residents also.13,20,21

This study provides additional evidence that cognitively impaired nursing home residents pose special challenges for care providers concerned with residents’ quality of life, including at the end of life. Measuring the quality of life of nursing home residents with end-stage dementia should continue to be a priority area for research, particularly since cognitively impaired nursing home residents may be less likely to receive hospice care, in part due to the difficulties in determining their prognosis. The results of one study demonstrated that while only 1.1% of residents with advanced dementia were perceived by nursing home staff as having a life expectancy of six months or less, 71% died within that period.22

The role of hospice nurses and paraprofessional staff in the long-term care setting is critically important, and increasing access to hospice services for all nursing home residents should be encouraged.23 Hospice presence in the nursing home has been associated with fewer hospitalizations and superior pain management, as well as better symptom assessment and management for both residents enrolled in hospice and other residents.14,24 However, while the presence of hospice in nursing homes is growing, from 13% in 1997 to more recent estimates as high as 46%,23,25 overall, only 1% of the nursing home population is enrolled in hospice.26

This study has limitations that must be noted. The relatively small sample size limits our ability to generalize these findings to other communities and patient populations. West central Florida contains six counties in which the mean age is over 55 years,7 and is also home to nearly a third of the skilled nursing facilities in the state, as well as the two largest not-for-profit hospice organizations in the United States. The sample surveyed also had uncharacteristically long average job tenure,
and length of work history has been correlated with nurses' feelings of empowerment.\textsuperscript{24}

The relatively high scores overall and limited variability among scores can also make interpretation problematic. The high overall ratings revealed that all respondents perceived that quality-of-life domains were important and that they could influence them for both physically and cognitively impaired nursing home residents near the end of life. The highly subjective way in which questions were asked in the survey questionnaire might be refined with the use of descriptive patient vignettes, rather than asking respondents to picture a hypothetical resident with cognitive or physical impairments.\textsuperscript{14} Few long-term care residents are either solely cognitively or physically impaired, which also limits the realism of the patient descriptions.

Finally, the domains identified for measuring quality of life in the nursing home setting included in this study may not reflect domains that are relevant for quality of life at the end of life. It is interesting to note that freedom from pain and spiritual well-being, two hospice competencies that are key components of end-of-life care, were rated comparably by hospice staff members and nursing home staff members. The inclusion of other domains such as life closure and others emphasized by hospice organizations and staff members might lead to different results, and may have implications for the inclusion of other domains as indices of nursing home residents' quality of life at the end of life. To accurately measure quality of life at the end of life, measurement instruments that equate quality of life with improvements in functional competence need to be modified to take into account the changing priorities, preferences, and needs that often accompany the transition to the end of life.

Efforts to improve end-of-life care in the long-term care environment should continue to focus on increasing hospice presence in nursing homes. In addition, staff training in palliative and end-of-life care for nursing home staff can reinforce the benefits for residents, families, and staff of partnerships with hospice organizations in caring for patients at the end of life. To be successful, such training programs must take into account the particular regulatory environment of nursing homes, which tend to emphasize security, functional competency, and the avoidance of negative medical outcomes, and should incorporate the competencies and models of care of hospice providers. These results suggest that the effectiveness and impact of hospice presence in nursing homes should be measured not only in terms of resident and family perceptions of quality of life and satisfaction with care, but also in improvements in nursing home staff members’ skill acquisition and attitudes toward end-of-life issues.

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