

Late Transitions and Bereaved Family Member Perceptions of Quality of End-of-Life Care

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OBJECTIVES: To examine associations between health-care transitions at the end of life (EOL; late transitions) and bereaved family members' and friends' assessment of EOL quality of care (QOC).

DESIGN: National Health and Aging Trends Study (NHATS), a prospective cohort of Medicare enrollees aged 65 and older.

SETTING: United States, all sites of death.

PARTICIPANTS: Family members and close friends of decedents from NHATS Rounds 2 through 6 (N=1,653; weighted 6.0 million Medicare deaths).

MEASUREMENTS: Multivariable logistic regression with survey weights was used to examine the association between having a late transition and reports of perceived unmet needs for symptom management, spiritual support, concerns with communication, and overall QOC.

RESULTS: Seventeen percent of decedents had a late transition. Bereaved respondents for decedents experiencing late transitions were more likely to report that the decedent was treated without respect (21.3% vs 15.6%; adjusted odds ratio (AOR)=1.59, 95% confidence interval (CI)=1.09–2.33), had more unmet needs for spiritual support (67.4% vs 55.2%; AOR=1.48, 95% CI=1.03–2.13), and were more likely to report they were not kept informed about the person's condition (31.0% vs 20.9%; AOR=1.54, 95% CI=1.07–2.23). Bereaved respondents were less likely to rate QOC as excellent when there was a late transition (43.6% vs 48.2%; AOR=0.79, 95%

CI=0.58–1.06). Subgroup analyses of those experiencing a transition between a nursing home and hospital (13% of all late transitions) revealed such transitions to be associated with even worse QOC.

CONCLUSION: Transitions in the last 3 days of life are associated with more unmet needs, higher rate of concerns, and lower rating of QOC than when such late transitions are absent, especially when that transition is between a nursing home and hospital. *J Am Geriatr Soc* 66:1730–1736, 2018.

Key words: healthcare transitions; quality of care; end-of-life care

Healthcare transitions have been shown to put individuals and their families at risk of fragmentation of care, medical errors, and unnecessary diagnostic testing.^{1–4} A study of nursing home residents found that 3 types of transitions were potentially burdensome: healthcare transitions in the last 3 days of life, lack of continuity in nursing homes after hospitalization in the last 90 days of life, and multiple hospitalizations in the last 90 days of life for expected conditions while dying.⁵ The study showed that nursing home residents in regions of the country with high rates of these transitions were more likely to have a feeding tube, had greater intensive care unit use in the last month of life, and were more likely to have a Stage IV decubitus ulcer. Despite evidence that burdensome transitions at the end of life (EOL) may be associated with markers of poor quality of care (QOC), the number of late healthcare transitions at the EOL has been increasing over the past decade.⁶

Healthcare transitions in the last 3 days of life have been studied as a marker of poor QOC based on expert opinion and prior study of persons dying in nursing homes,⁷ but no study has shown whether bereaved family members report different perceptions of QOC when their family member has a transition in the last 3 days of life. We hypothesized that numerous problems may arise

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during late transitions, such as family having to meet an unfamiliar care team, delays in needed medication for symptom management, and breakdown in communication during a vulnerable time. Self-reported outcomes provide a reliable, valid consumer perception of QOC at the EOL.^{8–10} Although people are often too sick or debilitated at the EOL to participate in interviews, family members can reliably report on their relative's experience.¹¹ Bereaved family member survey tools have been developed and validated,^{12,13} and caregiver interviews have been shown to correlate with QOC at the EOL.^{13–16}

The primary aim of this study was to examine the relationship between healthcare transitions in the last 3 days of life (late transitions) and EOL QOC. Information from surveys of family members of deceased National Health and Aging Trends Study (NHATS) participants was examined to analyze whether late transitions to locations other than home were associated with bereaved family member perceptions of unmet needs, problems in communication, and concerns with QOC. We also sought to determine whether there were differences in perceived quality when the transition was between a hospital and a nursing home.

METHODS

Study Population

NHATS is a nationally representative sample of Medicare enrollees aged 65 and older that started in 2011.¹⁷ NHATS used a stratified 3-stage sample design and over-sampled older persons and black individuals.¹⁸ Beginning in Round 2, a last-month-of-life (LML) interview was introduced and conducted with a proxy respondent to obtain information on the EOL experience of participants who died between rounds. The proxy respondent was usually a family member but could also be a close friend or other person with intimate knowledge of the participant. As part of the LML interview, proxy respondents were asked how familiar they were with the decedent's daily routine. To be included in the analysis, proxy respondents had to answer that they were at least somewhat familiar with the decedent's daily routine. We examined LML surveys for participants from 2012 to 2016 (Rounds 2–6). Unweighted response rates for the LML interview in Rounds 2 to 6 were between 94.1% and 96.4%.¹⁹ Of 2,212 decedents with completed LML interviews, 1,653 with a family or friend proxy who was at least somewhat familiar with the decedent's daily routine were included in the analysis (weighted 6.0 million deaths).

Measures

The main exposure of interest was having had a late healthcare transition. Proxy respondents were not asked directly whether the decedent had had a late transition; those who reported that the decedent died somewhere other than home were asked how long they had been at that location before dying. Decedents with a duration of 3 days or less were considered to have had the exposure. Options for place of death included their own or another's

home, nursing home, hospital, or palliative care unit or hospice residence. For decedents who died in places other than home, respondents were also asked where the decedent had been just before the place of death. Options for location before death included the decedent's own or another's home, nursing home, hospital, or hospice residence. Because late transitions to home were not captured in the LML interview, they are not represented in the analysis. If a decedent experienced a late transition from a nursing home to a hospital or from a hospital to a nursing home, they were considered to have had an institution-to-institution transition.

The main outcome of interest was perceived quality of EOL care as reported by the proxy (bereaved LML respondent). Items included unmet needs (e.g., for pain management, dyspnea management, anxiety and sadness, spiritual support) and interactions with the care team (e.g., how often the decedent was treated with respect, adequacy of individual and family involvement in care decisions, how often family was kept informed of the decedent's condition, whether the decedent received care that he or she would not have wanted). For unmet needs, those who did not experience a certain symptom in the last month of life were considered to have no unmet needs for that symptom. LML respondents were also asked how they would rate the decedent's overall QOC in the last month of life (excellent, very good, good, fair, poor). (See Supplementary Table S1 for specific questions.)

Basic demographic information including age, race, and ethnicity was available for each decedent. During initial enrollment in NHATS and with each subsequent round of interviews, participants reported physician-diagnosed medical problems. We compared decedents according to the presence of 6 major medical comorbidities (including prevalent cases in 2011 and incident cases during the study period): heart disease, diabetes mellitus, lung disease, stroke, dementia, and cancer. To measure functional status, decedents who got out of bed only some days, rarely, or never in the last month of life and those who were never alert during the last month of life were classified as having low functional status. Information on the relationship between proxy respondents and decedents was collected and reported.

Statistical Analysis

A binary variable for a late transition to a location other than home was created. Similarly, we created an indicator for having experienced an institution-to-institution transition that reflected a transition between acute care hospital and nursing home. We fit logistic regression models to study the association between having a late transition and each different measure of QOC. In addition to unadjusted models, models adjusted for age, sex, race, relationship of bereaved respondent, functional status, and comorbidities were included in the multivariable model. All analyses incorporated survey weights to account for the complex survey design of NHATS.

It is likely that decedents who had trouble getting out of bed in the last month of life were sicker and more functionally impaired than the study population as a whole.

To explore any differences in this subpopulation, we performed a sensitivity analysis fitting adjusted logistic regression models on the subset of the sample who had difficulty getting out of bed in the last month of life. We performed an additional sensitivity analysis restricted to respondents who were very familiar with the decedent's routine.

All analyses were performed using Stata version 14.2 (Stata Corp., College Station, TX). Because we relied on de-identified data, the Brown University institutional review board determined that this project did not qualify as human subjects research.

RESULTS

Decedent Characteristics

Table 1 shows baseline characteristics of decedents in the cohort according to late transition status. Overall, the distributions of race, age, and relationship to proxy respondent were similar between the 2 groups. A larger percentage of those not experiencing a late transition than of those experiencing a late transition had difficulty getting out of bed in the last month of life (49.5% vs 23.2%, $p < .001$). Those who experienced a late transition were less likely to have heart disease (7.0% vs 10.9%, $p = .03$) and cancer (14.0% vs 17.7%, $p = .04$) than those who did

not experience a late transition (Table 1). The most common type of late transition (47.4%) was from home to hospital. (See Supplementary Table S2 for all transition types.)

Any Transition in Last 3 Days of Life and QOC

Seventeen percent of decedents ($n = 272$, weighted $n = 1.0$ million) experienced a late transition to a location other than home. Having experienced a late transition was associated with certain markers of worse QOC at the EOL (Table 2). Respondents reported more unmet needs for spiritual support when the decedent experienced a late transition (adjusted odds ratio (AOR)=1.48, 95% confidence interval (CI)=1.03–2.13). Decedents experiencing a late transition were also more likely not always to be treated with respect (AOR=1.59, 95% CI=1.09–2.33), and their families were more likely not always to be informed of their condition (AOR=1.54, 95% CI=1.07–2.23). Although not reaching conventional levels of statistical significance ($p < .05$), for those who experienced a late transition, there was a pattern of being more likely to report unmet needs for pain, dyspnea, and anxiety and sadness management; receive care not consistent with decedent goals; and have inadequate communication regarding care decisions (Table 2). Respondents of decedents who experienced a late transition were less likely to

Table 1. Characteristics of Decedents in Study Population

Characteristic	Late Transition, n = 272 (Weighted n = 1.0 Million)	No Late Transition, n = 1,381 (Weighted n = 5.0 Million)	P-Value
	n (%)		
Race and ethnicity			
White, non-Hispanic	173 (63.6)	864 (62.6)	.93
Black, non-Hispanic	59 (21.7)	275 (19.9)	.55
Hispanic	8 (2.9)	69 (5.0)	.07
Other	12 (4.4)	38 (2.8)	.15
Don't know, missing	20 (7.4)	135 (9.8)	.14
Age at death			
65–69	7 (2.3)	78 (5.6)	.01
70–74	29 (10.7)	112 (8.1)	.08
75–79	36 (13.2)	164 (11.9)	.33
80–84	54 (19.9)	273 (19.8)	.31
84–89	64 (23.5)	324 (23.5)	.92
≥ 90	82 (30.1)	430 (31.1)	.78
Proxy respondent			
Spouse	63 (23.2)	302 (21.9)	.41
Child	145 (53.3)	779 (56.4)	.30
Other family	38 (14.0)	133 (9.6)	.10
Friend, non-family	26 (9.6)	167 (12.1)	.38
Had difficulty getting out of bed in last month of life	63 (23.2)	684 (49.5)	<.001
Comorbidities			
Heart disease	19 (7.0)	151 (10.9)	.03
Diabetes mellitus	18 (6.6)	123 (8.9)	.11
Lung disease	19 (7.0)	130 (9.4)	.15
Stroke	22 (8.1)	159 (11.5)	.25
Dementia	20 (7.4)	165 (11.9)	.34
Cancer	38 (14.0)	245 (17.7)	.04

Some column totals for percentages do not equal 100 because of rounding differences.

Table 2. Associations Between Bereaved Family Member Perceptions of Quality of Care and Presence of a Late Transition in the Last 3 Days of Life

Variable	Late Transition, n = 272 (Weighted n = 1.0 Million)	No Late Transition, n = 1,381 (Weighted n = 5.0 Million)	Late Transition, Adjusted Odds Ratio (95% CI) ¹
	% (95% CI)		
Quality of care rated excellent	43.6 (37.2–50.2)	48.2 (44.9–51.0)	0.79 (0.58–1.06)
Unmet needs for pain management	27.5 (20.6–35.7)	21.4 (18.5–24.7)	1.20 (0.74–1.94)
Unmet needs for dyspnea management	24.7 (16.7–34.9)	18.5 (14.5–23.3)	1.15 (0.61–2.16)
Unmet needs for management of anxiety or sadness	53.7 (45.4–61.8)	45.3 (41.4–49.4)	1.32 (0.85–2.04)
Unmet needs for spiritual support	67.4 (60.5–73.5)	55.2 (51.1–59.3)	1.48 (1.03–2.13)
Not always treated with respect	21.3 (16.0–27.8)	15.6 (13.6–17.9)	1.59 (1.09–2.33)
Care not consistent with goals	14.3 (10.3–19.6)	12.0 (10.1–14.1)	1.23 (0.77–1.96)
Inadequate communication about care decisions	10.6 (7.1–15.5)	8.9 (7.3–10.7)	1.33 (0.75–2.36)
Family not always kept informed of individual's condition	31.0 (24.3–38.6)	20.9 (18.7–23.2)	1.54 (1.07–2.23)

¹Adjusted for age, sex, race, ethnicity, comorbidities, relationship to proxy, and functional status.
CI = confidence interval.

report that overall EOL QOC was excellent (AOR=0.79, 95% CI=0.58–1.06, $p=.05$). In sensitivity analyses examining the subset of decedents who had difficulty getting out of bed and the subset of respondents who were very familiar with the decedent's routine, similar patterns were observed (Supplementary Tables S3 and S4).

Institution-to-Institution Transition in the Last 3 Days of Life and QOC

Thirteen percent of late transitions were between hospital and nursing home ($n=42$, weighted $n=131,731$). Having experienced an institution-to-institution late transition (from nursing home to hospital or from hospital to nursing home) was associated with worse perceived QOC for several outcomes than not having a late transition or having a noninstitution late transition (Figure 1). Bereaved respondents reported more unmet needs for anxiety and sadness management when the decedent experienced an institution-to-institution late transition (AOR=3.66, 95% CI=1.34–10.02). Decedents experiencing an institution-to-institution late transition were also more likely to receive care inconsistent with their goals (AOR=3.44, 95% CI=1.75–6.77) and receive inadequate communication about care decisions. (AOR=3.37, 95% CI=1.45–7.79). Although not reaching conventional levels of statistical significance, for those who experienced a late institution-to-institution transition there was a pattern of reports of unmet needs for pain and dyspnea management, decedent not always being treated with respect, and family not being always informed of decedent condition (Table 3). When qualitatively compared with the AORs for any late transition in Table 2, the effect size of an institution-to-institution late transition on QOC was of higher magnitude across most outcome measures.

DISCUSSION

Using a nationally representative sample of older Americans, we found that bereaved family members or close friends report more unmet needs, higher rates of concerns, and lower rating of QOC when there is a healthcare transition in the last 3 days of life. Experiencing a late transition between nursing home and hospital was associated with even lower QOC; only 32.1% of those who experienced that transition said care was excellent, compared with 48.2% who did not have a late transition. Despite the observed rise since 2000 in the number of Americans experiencing healthcare transitions at the EOL,⁶ little is known about how such transitions affect perceptions of the QOC received. Prior qualitative studies of individuals and their caretakers have revealed problems in communication, difficulty contacting providers when needed, and lack of needed information during care transitions,^{20–23} but previous work on transitions has not examined a population of actively dying persons, who often have complex medical and social needs. That type of population was the focus of this study. Increasing attention and interventions are needed to improve healthcare transitions in actively dying persons.

Although many of the CIs for the AORs in our study crossed 1, the effects were consistently in the direction hypothesized, and the effect sizes, particularly for the institution-to-institution transitions, were large. Numerous critiques of relying on p-values for inference have been proposed,²⁴ and we assert that focusing on estimation and presenting a measure of uncertainty using CIs, as others have suggested,²⁵ allows us to draw relevant conclusions from these data. Our study found a high prevalence of unmet needs and inadequate communication with those who experienced a late transition, with only 44% reporting excellent EOL QOC. These problems were more

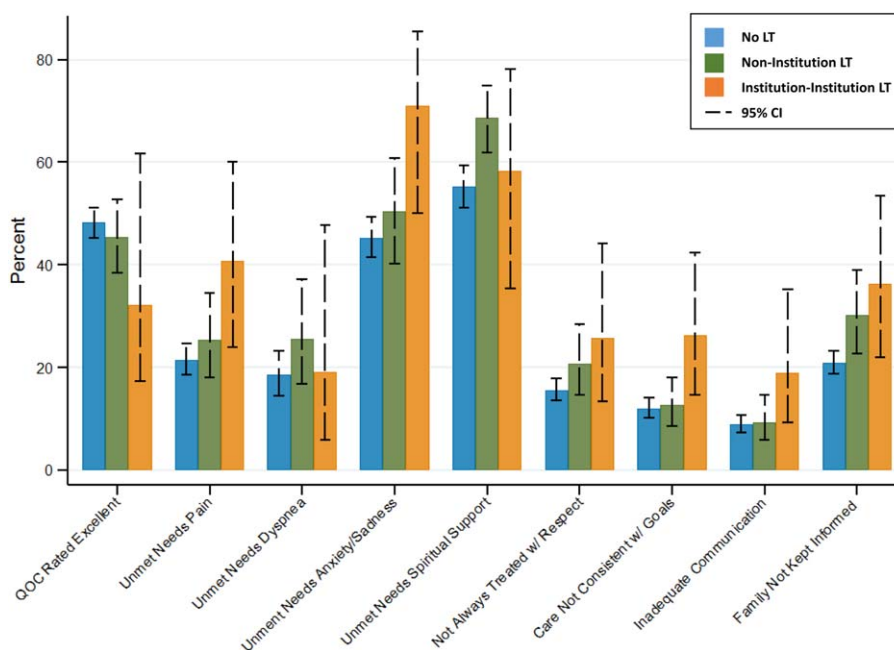


Figure 1. Respondent reports of quality of care (QOC) according to whether decedent had no late transition (LT), any LT, or an institution-to-institution LT. Height of bars is the proportion of respondents who had a positive answer for each quality of care measure on the x-axis.

prevalent when a decedent experienced a late transition in either direction between a hospital and nursing home. Although a 4–percentage point difference in reported excellent QOC between those who did and did not experience a late transition (44% vs 48%) may seem small, recent studies have shown that even very small differences in patient-reported quality ratings can translate into meaningful differences in disenrollment from health plans²⁶ or willingness to recommend hospice programs.²⁷ With nearly 20% Americans in this study experiencing a late transition and 13% of these experiencing a transition between a hospital and a nursing home, this is a subpopulation of vulnerable individuals for whom important opportunities exist to improve QOC.

Numerous factors may be involved in making transitions between hospitals and nursing homes particularly detrimental at the EOL. Actively dying persons often have complex medical problems and numerous needs for symptom management. When transitioning between hospitals

and nursing homes, communication of care plans may be incomplete; prescribing of pain medications may be delayed, leading to poorer symptom control; and individuals and family members must become acquainted with a new care team. Family members of individuals dying in nursing homes often feel that nursing home staff have not prepared them for what to expect in the dying process,²⁸ that the needs of their dying family members are inadequately met, and that nursing home staff are not sufficiently trained to provide appropriate EOL care,²⁹ creating a greater burden for individuals and families to provide care through the dying process.³⁰ Although there has been extensive work on interventions to improve healthcare transitions for all persons, for example the Transitional Care Intervention^{31,32} and the Transitional Care Model,³³ more focused research is needed to understand how to improve care transitions for actively dying persons, particularly late transitions between hospitals and nursing homes.

Table 3. Comparison of Quality of Care Between Institution-to-Institution Late Transitions and No Late Transition

Variable	Adjusted Odds Ratio (95% Confidence Interval) ¹
Quality of care rated excellent	0.46 (0.19–1.12)
Unmet needs for pain management	2.59 (0.84–8.01)
Unmet needs for dyspnea management	1.15 (0.26–5.05)
Unmet needs for management of anxiety or sadness	3.66 (1.34–10.02)
Unmet needs for spiritual support	1.02 (0.35–2.97)
Not always treated with respect	2.06 (0.69–6.17)
Care not consistent with goals	3.44 (1.75–6.77)
Inadequate communication about care decisions	3.37 (1.45–7.79)
Family not kept informed of individual's condition	2.12 (0.87–5.18)

¹Adjusted for age, sex, race, ethnicity, comorbidities, relationship of proxy, and functional status.

More research is needed to understand the nature of the association between late transitions and bereaved family member perceptions of EOL QOC. This study could not determine causality, and it is possible that experiencing a late transition may be a marker of other problematic characteristics of EOL care. For example, in some cases, the transition may be welcome, but the care before or after the transition leaves unmet needs for symptom management and poor communication with individuals and families. Further studies are needed to identify subsets of actively dying individuals who may benefit most from interventions to avoid late transitions when possible and improve transitions that must occur. Prior studies have shown that different diseases may lead to different trajectories of functional decline and death.^{34–36} This study did not attempt to differentiate between decedents who had different disease trajectories, and it is possible that those with more chronic illness and predictable disease course may benefit from different interventions than those with acute, precipitous declines. For example, those with acute declines may benefit from a sort of “rapid response” hospice team that is specially trained and equipped to address the needs of these individuals. Although our sensitivity analyses showed a consistent pattern of worse perceptions of EOL QOC in individuals who probably had a more predictable decline, a useful next step would be to more accurately categorize different types of individuals, although for all individuals, we propose that late transitions may serve as a population-based measure for quality improvement.

This study has a number of potential limitations. We analyzed bereaved family member perceptions in which respondents are asked to serve as proxies for the decedent, as well as represent their own perceptions of care (e.g., whether they were kept informed about the individual’s condition). Although we cannot be sure that proxy answers align with what the decedent would have reported, family member respondents have been shown to provide reliable information on EOL QOC.¹¹ There were several limitations of the study design; the sample size of the subgroup analysis of those with institution-to-institution transitions was small; because of sample size limitations, some results suggested differences but did not reach conventional levels of statistical significance; we could not comment on causality given the observational design; and we could not identify late transitions to home. Strengths included using a nationally representative sample to analyze late transitions in a population of dying individuals, using bereaved family member and friend reports to obtain a person-centric view of EOL QOC, and being able to identify location-specific transitions that are particularly problematic (e.g., between nursing homes and hospitals).

In conclusion, there is an important opportunity to improve healthcare transitions in the last days of life, particularly when these transitions occur between hospitals and nursing homes. There are numerous avenues to improve the care of persons experiencing late transitions, including better advanced care planning to avoid unnecessary transitions when possible and innovative communication modalities to ensure that individual and family needs and concerns are met in those transitions that are appropriate.

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SUPPORTING INFORMATION

Table S1. NHATS LML Interview Questions Regarding EOL QOC

Table S2. Number and Proportion of All Late Transitions by Type

Table S3. Associations Between Bereaved Family Member Perceptions of the Quality of Care and Presence of a Late Transition in the Last Three Days of Life for Those with Poor Functional Status

Table S4. Associations Between Bereaved Family Member Perceptions of the Quality of Care and Presence of a Late Transition in the Last Three Days of Life for Deceaseds with Respondents "Very Familiar" with Routine

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