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

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Abstract

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Background/Objective: Health care transitions in the last three days of life have increased in the United States. We aimed to examine the impact of transitions in the last three days of life on bereaved family members' and friends' assessment of the quality of end-of-life care.

Design: National Health and Aging Trends Study (NHATS), a prospective cohort of Medicare enrollees age ≥ 65.

Setting: United States, all sites of death.

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

Exposure: Medicare decedents' experiencing a transition between any location and a healthcare institution in the last three days of life.

Measurements: Multivariable logistic regression with survey weights examined the association between having a late transition and reports of perceived unmet needs for symptom management, spiritual support, concerns with communication, and overall care quality (QOC).

Results: Seventeen percent of decedents experienced a late transition. Bereaved respondents for decedents experiencing late transitions were more likely to report that their loved one was treated without respect (adjusted odds ratio (AOR) 1.59, 95% confidence interval (CI): 1.09 – 2.33), had more unmet needs for spiritual support (AOR 1.48, 95% CI: 1.03 – 2.13), and were more likely to report they were not kept informed about patients' condition (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 (AOR 0.79, 95% CI: 0.58 – 1.06). Sub-group 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 three days of life are associated with more unmet needs, higher rate of concerns, and lower rating of quality of care, especially when that transition is between a nursing home and hospital.

Key Words: Healthcare transitions, quality of care, End-of-Life care

Introduction

Health care transitions have been shown to put patients and their family at risk for fragmentation in care, medical errors and unnecessary diagnostic testing.[1–4] Previously, in a study of nursing home patients, Gozalo and colleagues[5] proposed three transitions as potentially burdensome: 1) healthcare transitions in the last three days of life; 2) lack of continuity in nursing homes post-hospitalization in the last 90 days of life; 3) multiple hospitalizations in the last 90 days of life for expected complications while dying. They 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 increased intensive care unit (ICU) utilization in the last month of life and were more likely to suffer a stage IV decubitus ulcer. Despite evidence that burdensome transitions at the end of life may be associated with markers of poor quality of care, the number of late healthcare transitions for patients at the end of life has been increasing over the past decade.[6]

Teno and colleagues have studied healthcare transitions in the last three days of life as a marker of poor quality of care based on expert opinion and prior study of persons dying in nursing homes.[7] No study has yet shown, however, whether bereaved family members report different perceptions of the quality of care when their family member has a transition in the last three days of life. We hypothesize that numerous problematic issues may arise 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 for patients. Patient reported outcomes provide a reliable and valid consumer perception of quality of care at the end

of life.[8–10] While patients at the end of life are often too sick or debilitated to participate in interviews, family members can reliably report on their loved one's experience.[11] Bereaved family member survey tools have been developed and validated,[12,13] and caregiver interviews have been shown to correlate with quality of care at the end of life.[13–16]

The primary aim of this study was to examine the relationship between healthcare transitions in the last three days of life and end-of-life quality of care. Information from bereaved family member surveys of deceased patients from the National Health and Aging Trends Study (NHATS) was examined to analyze if health care transitions in the last three days of life to locations other than home were associated with bereaved family member perceptions of unmet needs, problems in communication and concerns with quality of care. We also sought to identify if 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 in the US age 65 or older that started in 2011.[17] NHATS utilized a stratified three-stage sample design, and oversampled persons at older ages 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 end-of-life 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 2012-2016 (rounds 2-6). Unweighted response rates for the LML interview in rounds 2-6 were between 94.1% and 96.4%.[19] Out of a total 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 healthcare transition in the last three days of life. Proxy respondents were not asked directly whether or not their loved one had a transition in the last three days of life. Rather, those who reported that their loved one died somewhere other than home were asked how long the decedent had been at that location prior to dying. Those who answered duration of ≤ 3 days were considered as having the exposure. Options for place of death included their own or another's home, nursing home, hospital or hospice residence. All proxy respondents were also asked where the decedent resided just before the place of death. Options for location prior to death included the decedent's own or another's home, nursing home, hospital or hospice residence. Transitions to home were not captured in the LML interview and so could not be included 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 an institution-to-institution transition.

The main outcome of interest was perceived quality of end-of-life care as reported by the proxy (bereaved LML respondent). Items included unmet needs (e.g. for pain management, dyspnea management, anxiety and sadness, and 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, and whether the decedent received care that he/she would not have wanted). LML respondents were also asked how they would rate the decedent's overall quality of care in the last month of life (excellent, very good, good, fair, or poor) (see Table S1 for specific questions).

Basic demographic information including age and race/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 by the presence of six major medical comorbidities (including both prevalent cases in 2011 and incident cases during the study period): heart disease, diabetes mellitus, lung disease, stroke, dementia and cancer. As a measure of functioning at the end of life, we compared decedents on ability getting in and out of bed in the last month of life. Those who were not alert in the last month of life were considered as having difficulty getting in and out of bed. Information on the relationship of the proxy respondent for each decedent was collected and reported. 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.

Statistical Analysis

A binary variable for the presence of a transition in the last three days of life to locations other than home was created. Similarly, we created an indicator for having experienced an institution-to-institution transition that reflected a transition between an acute care hospital and nursing home. We fit logistic regression models to study the association of having a late transition with each different measure of quality of care. In addition to unadjusted models, models adjusted for age, sex, race, relationship of bereaved respondent, functional status (as measured by ability to get out of bed in the last month of life) and comorbidities were included in the multivariable model. All analyses incorporated survey weights to account for the complex survey design of NHATS.

All analyses were performed using Stata 14.2 statistical package. As 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. Overall, 79% of decedents were white and 10% black, with a similar distribution between those experiencing a late transition and those not. A higher percentage of decedents who did not experience a late transition were Hispanic compared to those who did (7% vs. 4%, $p= 0.07$). The age of death distribution was similar between groups, but a higher percentage of those not experiencing a late transition had difficulty getting out of bed in the last month of life (48% vs. 24%, $p < 0.001$). There were more medical co-morbidities among the group that did not experience a late transition (see Table 1).

Any Transition in Last Three Days of Life and Quality of Care

Seventeen percent of decedents (N = 283, weighted N = 1.0 million) experienced a transition in the last three days of life to a location other than home. Having experienced a late transition was associated with worse quality of care at the end of life (Table 2). Bereaved family or close friend respondents reported more unmet needs for spiritual support when their loved one experienced a late transition (AOR 1.48, 95% CI: 1.03 – 2.13). Decedents experiencing a late transition were also more likely to not always be treated with respect (AOR 1.59, 95% CI: 1.09 – 2.33), and their families were more likely to not always be informed of their condition (AOR 1.54, 95% CI: 1.07 – 2.23). While not reaching statistical significance, for those who experienced a late transition there was a pattern of being more likely to report: unmet needs for pain, dyspnea and anxiety/sadness management; receiving care not consistent with decedent goals; and having inadequate communication regarding care decisions (Table 2). Respondents of decedents who experienced a late transition also were less likely to report that the overall quality of care their loved one received at the end of life was excellent (AOR 0.79, 95% CI: 0.58 – 1.06).

Institution-to-Institution Transition in the Last Three Days of Life and Quality of Care

Thirteen percent of late transitions were between a hospital and a nursing home (N=36, weighted N = 131,731). Having experienced an institution-to-institution late transition (from nursing home to hospital or from hospital to nursing home) in the last three days of life was associated with worse perceived quality of care than having no late transition or having a non-institution late transition (Table 3). Bereaved respondents reported more unmet needs for anxiety and sadness management when their loved one

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). When compared to any late transition, the effect size of an institution-to-institution late transition on quality of care was of higher magnitude across all outcome measures.

Discussion

Health care transitions are associated with medical errors and lack of care coordination.[1–4] Transitions in the last three days of life have been increasing over the past decade, raising concerns that such transitions may be burdensome for family and close friends of dying patients who have to deal with a new set of health care providers while coping with the impending death of a loved one. 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 the quality of care when there is a health care transition in the last three days of life. Experiencing a transition between a nursing home and hospital in the last three days of life was associated with even lower quality of care; only 32.1% who experienced that transition said care was excellent compared to 48.2% who did not have a health care transition in the last three days of life. Increasing attention and interventions are needed to improve healthcare transitions in actively dying persons.

Since 2000, an increasing number of Americans have experienced healthcare transitions at the end of life.[6] Despite this observed rise, little is known about how such healthcare transitions at the end of life affect perceptions of the quality of care received.

Prior qualitative studies of both patients and their caretakers have revealed problems in communication, difficulty contacting providers when needed and lack of needed information during care transitions.[20–23] Previous work on transitions, however, has not dealt with a population of actively dying persons, who often have more complex medical and social needs. This population was the focus of this study.

Our study found a high prevalence of unmet needs and inadequate communication among those who experienced a late transition, with only 44% reporting excellent quality of end-of-life care. These problems were more prevalent when a decedent experienced a late transition in either direction between a hospital and nursing home. With nearly one in five Americans in this study experiencing a late transition in the last three days of life, and 13% of these experiencing a transition between a hospital and a nursing home, this is a sub-population of vulnerable patients where important opportunities exist to improve the quality of care.

Numerous factors may be involved in making transitions between hospitals and nursing homes particularly detrimental at the end of life. 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 family members and patients must reacquaint with a new care team. Work by Wetle et al. suggests that family members of individuals dying in nursing homes often feel unprepared by nursing home staff about what to expect in the dying process,[24] that the needs of their dying loved ones are inadequately met, and that nursing home staff are not sufficiently trained to provide appropriate end-of-life care,[25]

creating increased burden on patients and families to provide care through the dying process.[26]

More research is needed to identify interventions that could improve the quality of care for patients experiencing such institutional late transitions. For example, the rapid dissemination of telecommunication technologies provides potential opportunities for improving communication of care plans in advance of transfers. Other alterations in care processes, such as early ordering of opiate medications prior to patient's arrival, may help avoid delays in symptom management. While there has been extensive work on interventions to improve healthcare transitions experienced by all persons, for example the Transitional Care Intervention from Coleman and colleagues[27,28] and the Transitional Care Model from Naylor and colleagues,[29] more focused research is needed to understand how to improve care transitions for actively dying persons. Novel approaches that take into account the unique needs of those at the end of life, particularly those focusing on late transitions between hospitals and nursing homes, would be especially valuable.

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 respondent for their own perceptions of care (e.g. whether they were kept informed about the patient's condition). While 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 the quality of end-of-life care.[11] There were several limitations of the study design: 1) because of sample size limitations, some results suggested differences, but did not reach statistical significance,

2) inability to comment on causality given the observational design, and 3) the absence of information on transitions from other locations to home in the NHATS LML survey, thus preventing the assessment of the impact of late transitions to home. Strengths included: 1) using a nationally representative sample to analyze late transitions in a population of dying patients, 2) using bereaved family member and friend provided reports to obtain a patient-centric view of quality of care at the end of life, and 3) being able to identify location specific transitions that are particularly problematic (e.g. transitions specifically between nursing homes and hospitals).

In conclusion, there remains an important opportunity to improve health care transitions among persons in the last days of life, particularly when these transitions occur between hospitals and nursing homes. Numerous avenues exist to improve the care of persons experiencing transitions in the last days of life, including improved advanced care planning to avoid unnecessary transitions when able, and innovative communication modalities to ensure that needs and concerns of the patient and family are met in those that are appropriate.

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Tables

Table 1. Characteristics of decedents in study population

Characteristic	Overall N=1,653 (Weighted N = 6.0 million)	Late Transition N=283 (Weighted N = 1.0 million)	No Late Transition N=1370 (Weighted N = 5.0 million)
Race/ethnicity[a], % (95% CI)			
White, non-hispanic	79 (76–82)	80 (73–85)	79 (76–82)
Black, non-hispanic	10 (9-11)	11 (8-14)	10 (8-11)
Hispanic	7 (5-9)	4 (2-7)	7 (6-10)
Other	4 (3-6)	6 (3-12)	3 (2-6)
Age at death[a], % (95% CI)			
65-69	7 (6-9)	3 (1-6)	8 (6-11)
70-74	15 (13-17)	19 (14-27)	14 (12-16)
75-79	16 (14-19)	18 (13-25)	16 (14-18)
80-84	20 (18-22)	18 (13-23)	20 (18-23)
84-89	21 (19-23)	21 (17-27)	21 (19-24)
≥ 90	20 (18-22)	21 (17-25)	20 (18-22)
Proxy Respondent, % (95% CI)			
Spouse	28 (25-32)	31 (24-39)	28 (25-31)
Child	51 (48-55)	48 (40-56)	52 (48-56)
Other family	10 (8-12)	12 (9-17)	9 (7-11)
Friend/Non-family	11 (9-13)	9 (5-14)	11 (9-13)
Had difficulty getting out of bed in last month of life, % (95% CI)	44 (41-46)	24 (18-32)	48 (45-51)
Comorbidities, % (95% CI)			
Heart disease	12 (10-14)	7 (3-12)	13 (11-15)
Diabetes Mellitus	11 (9-13)	8 (5-12)	11 (9-14)
Lung disease	11 (9-13)	8 (5-12)	11 (9-14)
Stroke	10 (9-12)	8 (5-12)	11 (9-13)
Dementia	9 (8-11)	7 (4-12)	10 (8-12)
Cancer	21 (18-23)	15 (11-21)	22 (19-25)

a. Where column total does not equal 100, due to rounding differences

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

Variable	Frequency, % (95% CI)		Adjusted Odds Ratio[a]
	Late Transition N=283 (Weighted N = 1.0 million)	No late transition N=1370 (Weighted N = 5.0 million)	Late transition (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 anxiety/sadness management	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 patient condition	31.0 (24.3 – 38.6)	20.9 (18.7 – 23.2)	1.54 (1.07 – 2.23)

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

Table 3. Associations Between Markers of Quality of Care and Presence of Late Transitions Between Nursing Homes and Hospitals in the Last Three Days of Life

Variable	Frequency, % (95% CI)			Adjusted Odds Ratio[a]
	No late transition N=1370 (Weighted N = 5.0 million)	Non-institution late transition N=246 (Weighted N = 899,261)	Institution-Institution Late transition N=36 (Weighted N = 131,731)	Institution-Institution Late transition v no late transition (95% CI)
Quality of care rated excellent	48.2 (45.3 – 51.1)	45.4 (38.4 – 52.7)	32.1 (17.3 – 51.7)	0.46 (0.19 – 1.12)
Unmet needs for pain management	21.4 (18.5 – 24.7)	25.4 (18.1 – 34.5)	40.7 (23.9 – 60.1)	2.59 (0.84 – 8.01)
Unmet needs for dyspnea management	18.5 (14.5 – 23.3)	25.6 (16.7 – 37.1)	19.1 (5.8 – 47.7)	1.15 (0.26 – 5.05)
Unmet needs for anxiety/sadness management	45.3 (41.4 – 49.4)	50.5 (40.2 – 60.8)	70.9 (50.0 – 85.5)	3.66 (1.34 – 10.02)
Unmet needs for spiritual support	55.2 (51.1 – 59.3)	68.7 (61.8 – 74.9)	58.3 (35.3 – 78.2)	1.02 (0.35 – 2.97)
Not always treated with respect	15.6 (13.6 – 17.9)	20.7 (14.6 – 28.4)	25.8 (13.3 – 44.2)	2.06 (0.69 – 6.17)
Care not consistent with goals	12.0 (10.1 – 14.1)	12.6 (8.5 – 18.1)	26.2 (14.7 – 42.3)	3.44 (1.75 – 6.77)
Inadequate communication about care decisions	8.9 (7.3 – 10.7)	9.3 (5.8 – 14.6)	19.0 (9.2 – 35.2)	3.37 (1.45 – 7.79)
Family not kept informed of patient condition	20.9 (18.7 – 23.2)	30.2 (22.7 – 38.9)	36.2 (21.9 – 53.4)	2.12 (0.87 – 5.18)

[a]Adjusted for age, sex, race/ethnicity, comorbidities, relationship of proxy, and functional status.