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End-of-Life Care Transition Patterns among Medicare Beneficiaries

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Abstract

Objective—To characterize the patterns of transitions in care and factors associated with multiple transitions in the last 6 months of life among decedents in the United States.

Design, Setting, and Participants—Retrospective study using data from all Medicare beneficiaries aged 66 years or older who died in July–December 2011.

Measures—Transitions between healthcare settings (e.g., hospital, skilled nursing facility, inpatient hospice, home hospice, and home without hospice) in the last 6 months of life. We summarized a count variable for number of transitions and produced Sankey diagrams to visualize

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the sequences of healthcare transitions. We used multivariable analyses to identify factors associated with an increased likelihood of having 4 transitions.

Results—Among 660,132 decedents, more than 80% (n=556,437) had at least one transition within the last 6 months of life. A total of 218,731 decedents had 4 transitions within the last 6 months of life. The most frequent transition pattern (19.3% of all decedents; n=127,435) followed this pathway: home to hospital, back to home or skilled nursing facility, to hospital again, and then to settings other than hospital, ending with 4 transitions. The average number of transitions in the last 6 months of life varied substantially across states, ranging from 1.8 in Alaska to 3.1 in New Jersey. Transitions became more intensive for decedents approaching death. In multivariable analyses, women, blacks, individuals younger than 85 years old, and individuals without dementia were more likely to have 4 transitions (P-values<0.05).

Conclusions—Approximately one-third of the Medicare beneficiaries who died in 2011 had 4 transitions within their last 6 months of life. Identifying interventions that can facilitate care transitions consistent with beneficiaries' preferences is warranted.

Keywords

Transitions in care; end-of-life care; Sankey diagram

INTRODUCTION

Care at the end of life is often fragmented and poorly coordinated among different health providers.^{1,2} Multiple transitions in care settings can be burdensome to patients and their families as well as costly to society.^{3,4} Recent data indicate that transitions across hospital, skilled nursing facility, nursing home, hospice, and home without Medicare-covered service in the last 90 days of life increased significantly, from 2.1 transitions per decedent in 2000 to 3.1 in 2009,⁵ and nearly 45% of decedents in 2009 had at least 1 care transition within the last 2 weeks of life.⁵

Despite these concerns about care transitions in the end of life, we lack contemporary data on the number, timing, and overall pattern of healthcare transitions in the last 6 months of life. One previous study reported the trend in transition prevalence over time⁵ but did not provide a comprehensive picture of transitions, including when transitions occurred; the sequence of various types of transitions; and, more importantly, the factors associated with transitions. Some studies have identified patient characteristics associated with multiple transitions, but only among patients with cognitive impairment⁶ or patients who were enrolled with hospice.⁷ As a result, we lack an adequate understanding of the level and type of care transitions in the last 6 months of life and of which types of patients are at risk of multiple transitions.

Accordingly, we sought to characterize the patterns of transitions in care and factors associated with multiple transitions in the last 6 months of life among decedents in the United States. To accomplish this, we analyzed Medicare claims data for all fee-for-service Medicare decedents who died in the period July-December 2011, and we used multivariable analyses to identify factors associated with the increased likelihood of having 4 transitions

of care within the last 6 months of life. We summarized a count variable for number of transitions and produced Sankey diagrams to visualize the sequences and timing of healthcare transitions. Characterizing such patterns of care is a critical step in the development of effective strategies to reduce the poorly coordinated quality and high cost of care at the end of life.

METHODS

Study design and sample

We conducted a retrospective analysis of all fee-for-service Medicare beneficiaries aged 66 years or older who died between July 1, 2011, and December 31, 2011. We limited our sample to beneficiaries who had both Medicare Parts A and B coverage. The study was reviewed by the Institutional Review Board of Yale University and was exempt from full review.

Definition of transition

Using Medicare claim files of inpatient, skilled nursing facility, and hospice services, we created a per-person chronological history of healthcare settings within the last 6 months of life on a daily basis.⁸ Depending on the type of claim, we included 5 healthcare settings, with a hierarchy from hospital, to skilled nursing facility, to inpatient hospice, to home hospice, to home. We used revenue center codes 0656 and 0657 in hospice claims to identify inpatient hospice care. We did not separate out nursing home care due to lack of identification in our data; thus, patients who resided in nursing homes and received hospice care within the nursing home were classified under “home hospice,” and patients who resided in nursing homes but were not receiving hospice care were classified under “home.” A transition was considered present when consecutive days of care were given in different healthcare settings. We thus excluded emergency department visits that did not result in a hospital admission from our definition of transition.

Other variables

Using data from the Master Beneficiary Summary File, we included covariates, such as patient age (categorized as 66–69 years, 70–74 years, 75–79 years, 80–84 years, and 85 years), race/ethnicity (non-Hispanic white, black, Hispanic, and other) and gender. We also ascertained chronic conditions, including heart disease (acute myocardial infarction, heart failure, and ischemic heart disease), Alzheimer’s disease or dementia, kidney disease, diabetes, chronic obstructive pulmonary disease or asthma, depression, stroke, and cancer (breast, colorectal, prostate, lung, and endometrial). Linking between decedents’ zip code information and the Area Resource File, we identified patient geographic factors, including metropolitan residence, median county-level income, and percentage of adults in the county with a high school education or less.

Statistical Analysis

We used standard descriptive statistics to summarize patient characteristics stratified by the number of healthcare transitions, using means for continuous variables and frequencies for categorical variables. We also calculated and ranked the mean number of transitions among

decedents in each state during the study period. Based on the healthcare setting for each person on each day in the last 6 months of life, we calculated the percentage of decedents who spent time in various healthcare settings and we depicted variations in transitions by geographical state. We summarized the sequences of transition using Sankey diagrams⁹ for the full cohort and for the geographic states with the highest and lowest number of transitions. Sankey diagrams, in which the width of each flow is shown proportionally to the flow quantity, have been used in science and engineering for decades.⁹

We calculated adjusted risk ratios using modified Poisson multivariate regression.^{10–12} The multivariate model was adjusted for the sociodemographic characteristics previously described. Standard errors of multivariate models are based on the robust (sandwich) variance estimator.¹¹ We used C++ to generate the transition data. The Sankey diagrams were created using web-based SankeyMATIC.¹³ All statistical analyses were completed using SAS, version 9.3 (SAS Institute, Cary, NC), and a two-tailed $p < .05$ was used to define statistical significance.

RESULTS

The full study sample consisted of 660,132 decedents. A total of 80.5% of decedents (N=556,437) had at least one transition in care in the last 6 months of life. Of all decedents, 39.6% (N=261,731) had four or more transitions, 13.1% (N=86,394) had three transitions, 14.3% (N=94,235) had two transitions, and 20.3% (N=134,101) had one transition. Decedents who had 4 transitions were more likely to be younger, non-white, and residing in metropolitan areas (Table 1). The average number of transitions in the last 6 months of life was 2.9 (median = 2, standard deviation = 2.8), varying substantially across states, from a low of 1.8 transitions in Alaska and 2.0 transitions in Utah to a high of 3.1 transitions in New Jersey (Figure 1).

The Figure 2 characterizes the sequences of transitions in the last 6 months of life for Medicare fee-for-service decedents in the United States. For instance, 87.3% of decedents stayed at home 180 days before death; of them, 18.0% died without transition, 68.1% were hospitalized as their first transition, 12.1% were enrolled with home hospice, 1.3% went to a skilled nursing facility, and 0.5% went to an inpatient hospice. Among the 405,913 beneficiaries whose first transition was to hospital, 17.5% died in hospital (without additional transition), 41.6% were discharged to their home, 29.2% to a skilled nursing facility, 11.0% to a home hospice, and 0.7% to an inpatient hospice. Among decedents with 4 or more transitions within the last 6 months of life (32.5% of all decedents), the most frequent transition pattern was patients moving from home to hospital, back to their home or a skilled nursing facility, to hospital again, and then to healthcare settings other than hospital (N=127,435).

The states of Utah and New Jersey have different patterns and sequences of healthcare transition (Supplementary Figures S1A and S1B; we chose the state of Utah instead of Alaska for the comparison purpose and sample size consideration). In Utah, 22.9% of residents died without any transition, 28.0% died with 1 transition, 15.7% died with 2 transitions, 11.8% died with 3 transitions, and 21.7% died with 4 or more transitions. In

contrast, in New Jersey, 18.3% of residents died without any transition, 18.9% died with 1 transition, 12.4% died with 2 transitions, 13.5% died with 3 transitions, and 37.0% died with 4 or more transitions. In both states, nearly 90% of decedents were at home at the date of 180 days prior to death, and approximately 25% of decedents died at home without receiving any services (Figure 3). The transitions became more intensive for decedents approaching death. In Utah, only 14.7% of decedents died in hospital, whereas in New Jersey 26.8% did so. In Utah, 54.7% of decedents died in home hospice, whereas in New Jersey only 40.4% did so.

In multivariable analyses, we found that decedents who were older, male, blacks, and had Alzheimer's disease or dementia were less likely to have 4 healthcare transitions, compared with decedents who were younger, female, non-Hispanic whites, and without Alzheimer's disease or dementia (Table 2). Compared with decedents aged 66 to 69, decedents aged 85 and older were less likely to have 4 healthcare transitions (adjusted risk ratio, 0.88; 95% confidence interval [CI], 0.87 to 0.90). Other variables associated with a significantly increased risk of having 4 healthcare transitions include female gender (adjusted risk ratio, 1.05; 95% CI, 1.04 to 1.05), blacks (adjusted risk ratio, 1.14; 95% CI, 1.13 to 1.15), residence in lower income areas (adjusted risk ratio, 1.10; 95% CI, 1.06 to 1.14), presence of heart disease (adjusted risk ratio, 1.22; 95% CI, 1.20 to 1.24), and presence of kidney disease (adjusted risk ratio, 1.27; 95% CI, 1.26 to 1.28). Sensitivity analyses, using 5 and 6 healthcare transitions as cut-off values, did not substantially change our results; however, Hispanics were more likely to have 5 or 6 healthcare transitions than were non-Hispanic whites (Supplementary Table S1).

Approximately two-thirds of decedents (67.6%) died at home, either receiving home hospice service or not receiving any service. The percentage of decedents who died at home also varied substantially across states, from 58.4% in New York to 79.6% in Utah. The median time at home between the final transition and death was 10 days, ranging from 5 days in New York, Connecticut, and Rhode Island to 70 days in Utah.

DISCUSSION

In this study, we found that more than 80% of Medicare fee-for-service decedents had at least one health care transition and approximately one-third had 4 transitions in the last 6 months of life, indicating that decedents frequently bounced in and out of healthcare settings. Such multiple transitions underscore concerns about fragmented care. In an attempt to understand these healthcare transitions, we investigated their detailed dynamics by presenting both sequences and timing of transitions. To our knowledge, this is the first study to use Sankey diagrams to depict the patterns of end-of-life transitions in care. Given that multiple transitions have the potential for fragmentation of care, efforts to reduce multiple transitions are greatly needed.

Building upon prior studies, our findings shed light on healthcare transitions in important ways. First, a large number of transition patterns are apparent in the last 6 months of life, with the most frequent transition pattern involving at least four transitions: home-hospital-home (or skilled nursing facility)-hospital-healthcare setting other than hospital. While the

prevalence of hospitalization is lower than that of hospice care or care in a skilled nursing facility (most of the time) at any point within the last 6 months of life, the first transition that decedents generally experienced was from home to hospital. Our results could help the health community and policy makers prioritize their efforts in order to reduce transitions. Given that most of the transition patterns involved hospitalization, where there are many interactions between patients (or their family members) and the healthcare system, strategies and interventions aimed at reducing healthcare transitions should target hospitalized patients. Hospital-based palliative care teams, which now exist in 67% of hospitals across the United States,¹⁴ are well positioned to provide consultations that include discussions about advance directives, hospice enrollments, and care plans for Medicare beneficiaries that could help patients and families rethink their preferences for care and potentially reduce unnecessary healthcare transitions.

Second, our results show substantial geographic variation in healthcare transitions. Compared with decedents in Delaware (ranking 26 in our sample), decedents in New Jersey, Illinois, Arkansas, or Florida were significantly associated with 4 transitions within the last 6 months of life. The mean number of care transitions across states differed, as well as the pattern of these transitions. Therefore, implementation of informational programs or incentives in states that are currently characterized by a large number of transitions may be effective for decreasing end-of-life care transitions. Utah might be used as a benchmark because approximately 20% of decedents transitioned from home to home hospice as their first transition, without transitioning into hospital. Policy makers in other states, in which the prevalence of the first transition from home to home hospice is lower, could put additional efforts into outpatient settings to encourage patient–provider discussions regarding the benefits of hospice services.

Third, our results raise concerns about underutilization of hospice services for some decedents. Among decedents who stayed at home 6 months prior to death, approximately one-fifth of them died without having any healthcare transition in their last 6 months of life; that is, these decedents did not use any health services we examined, including hospice enrollment. While some decedents may have died suddenly, we speculate that many of the decedents who did not have any transition may have needed hospice services but had difficulty accessing them. For instance, they may not have been aware of the benefits of hospice services. If hospice care is reliably better care for persons nearing death, identifying these patients and improving their access to hospice services could help decedents and their family members because hospice care is the gold standard for end-of-life care. We acknowledge that the merits of hospice for persons living with long-term disabling conditions is not well established.

We found several predisposing factors that were independently associated with multiple transitions. Beneficiaries who had heart, kidney, or lung diseases were at elevated risk to have multiple transitions. Attention should be focused on this category of beneficiaries to examine whether multiple transitions are consistent with beneficiaries' preferences or whether, instead, there is a system issue driving multiple transitions. Beneficiaries with these chronic conditions might be more vulnerable for poor care coordination and thus require expanding resources for care transitions, such as the services of transitional care programs.

For instance, several care transition programs, which are not necessarily specific to end-of-life care, have been developed and disseminated to promote smooth transitions and prevent hospital readmission.^{15–17} These programs, which include such services as helping patients to self-manage medication, scheduling follow-up care, and recognizing and responding to red flags,¹⁶ have been shown to reduce hospital readmission substantially.¹⁸

Although we followed the widely accepted definition of transitions in care,^{19,20} we recognize that not all transitions are the same. Transitions from hospital to home hospice or inpatient hospice are markers of “good” care, whereas transitions back and forth between hospital and home may be more indicative of fragmented care. Additionally, a certain number of transitions in care at the end-of-life period are necessary. For instance, in our world of seriously deficient caregiver support, many of these transitions could serve as respite for the caregiver. When the patient is in the hospital or SNF or inpatient hospice, the desperate caregiver could finally get some sleep, or feel that someone else is taking responsibility. Thus, we would not expect zero transitions within the last 6 months of life. In this study, we arbitrarily selected a cut-off value of 4 transitions, which generally involved at least two hospitalizations. We increased the cut-off value to 5 or 6 transitions in our sensitivity analyses, and the results are qualitatively similar. Further research is needed to identify the causes of care transitions and to examining care transitions that deviate from patient preferences.

Our study has several limitations. Because it is an observational study, we are unable to make any causal inferences. The results are also limited to fee-for-service Medicare beneficiaries, and could not be generalized to beneficiaries who were enrolled in Medicare Advantage Plans. Second, we lacked information about patient and family preferences and hence were unable to assess the impact of such transitions. A large number of transitions could result in fragmentation of care, could create burdens for patients and families, and may be inconsistent with the goal of care. Therefore, additional study, in which patient and family preferences can be elucidated and compared with these patterns of care, would be helpful. Third, we had data on hospital, skilled nursing facility, inpatient hospice, and home hospice, but we lacked data on nursing homes/assisted living facilities and on emergency department visits that did not result in a hospital admission. We therefore did not include transitions to/from a nursing home/assisted living facility or emergency department in our analyses. This would cause the number of transitions per decedent to be underestimated. For instance, including nursing homes or emergency department visits, Teno et al. found a mean transition number of 3.1 within the last 90 days in 2009 (compared with 2.9 transitions within the last 180 days in 2011 our study).⁵ We also did not include home care as a transition due to small number of decedents who were enrolled in home care, avoiding complicated figures. Finally, our retrospective cohort, created backward from decedents, may lead to biased conclusions for the number of care transitions across states because care received by decedents is not equivalent to care received by individuals who are dying.²¹ Future prospective study is needed.

In conclusion, nearly one-third of Medicare beneficiaries who died in 2011 experienced 4 transitions in health care within the last 6 months of life. Many of them transitioned across hospital, skilled nursing facility, and home but not hospice in their first three transitions.

Even though beneficiaries are hospitalized, early hospice referral is uncommon; approximately 12% of beneficiaries who were first admitted to a hospital transitioned to home hospice or inpatient hospice, indicating potential room for improvement. The measurement of transition across healthcare settings, potentially using data visualization efforts such as those as reported here, could be used to monitor the quality of end-of-life care at the state level.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.
Unadjusted Mean Number of Care Transitions in the Last 6 Months of Life by State

Figure 2.
Sequence of Care Transitions in the Last 6 Months of Life, for Medicare Decedents in the United States

Figure 3.
Locations in the Last 6 Months of Life, for Medicare Decedents in Utah (A) and New Jersey (B)

Table 1

Patient Characteristics, According to the Number of Healthcare Transitions

Characteristic	Transition=0 n=128,671 (19.5%)	Transition=1 n=134,101 (20.3%)	Transition=2 n=94,235 (14.3%)	Transition=3 n=86,394 (13.1%)	Transition 4 n=216,731 (32.8%)
Age in Years; mean (SD) ^a	82.5 (9.4)	83.1 (8.6)	83.5 (8.5)	82.6 (8.4)	81.9 (8.3)
Female (%) ^b	53.0	56.4	55.6	55.0	54.6
Race (%) ^b					
White	81.8	87.2	86.4	85.7	83.3
Black	8.3	6.5	7.7	7.9	10.0
Hispanic	5.7	3.6	3.6	4.0	4.3
Other	4.2	2.6	2.3	2.5	2.3
MSA (%) ^b					
No	10.6	9.6	9.8	9.7	9.4
Micropolitan	14.1	14.3	14.3	14.1	13.1
Metropolitan	75.3	76.1	75.9	76.2	77.5
Income (%) ^b					
< \$33,000	1.2	1.0	1.1	1.2	1.3
\$33,000–\$39,999	19.7	19.4	20.3	20.3	20.8
\$40,000–\$49,999	36.2	37.3	37.6	37.0	36.4
\$50,000–\$62,999	27.9	27.0	26.8	26.5	26.6
\$63,000	15.1	15.3	14.2	15.0	14.9
High School Education or less (%) ^b					
< 60%	0.1	0.1	0.1	0.1	0.1
60%–69%	2.2	2.0	2.0	2.2	2.3
70%–79%	16.8	15.5	15.6	16.3	16.6
80%–89%	61.1	61.4	62.0	61.7	62.4
90%	19.7	21.7	20.2	19.7	18.6
Chronic condition (%)					
Heart disease ^b	67.1	73.1	75.5	76.9	81.0
Alzheimer's/dementia ^b	44.7	42.9	44.6	39.6	38.2

Characteristic	Transition=0 n=128,671 (19.5%)	Transition=1 n=134,101 (20.3%)	Transition=2 n=94,235 (14.3%)	Transition=3 n=86,394 (13.1%)	Transition 4 n=216,731 (32.8%)
Kidney disease ^b	32.3	36.8	40.3	43.0	49.9
Diabetes ^b	38.4	40.7	42.9	45.1	50.3
Lung disease ^b	39.6	45.0	47.2	49.8	54.8
Depression ^b	40.4	41.4	42.5	41.4	43.3
Stroke ^b	26.2	28.2	30.1	29.2	31.8
Cancer ^b	17.7	24.6	24.0	26.4	26.9

MSA: Metropolitan statistical area; a metropolitan area contains a core urban area of 50,000 or more population, and a micropolitan area contains 10,000 to 50,000 population.

^a p-value <.001, paired-*t* test comparing between the transition = 0 group and the transition 4 group

^b p-value <.001, χ^2 test comparing between the transition = 0 group and the transition 4 group

Table 2

Adjusted Risk of at Least Four Healthcare Transitions in the Last 6 Months of Life among 660,130 Medicare Decedents

Factor	Adjusted Risk Ratio	95% Confidence Interval
Age		
66–69	reference	
70–74	1.00	0.99–1.01
75–79	1.01	0.99–1.02
80–84	0.99	0.97–1.00
85+	0.88	0.87–0.90
Female sex	1.05	1.04–1.05
Race		
White	reference	
Black	1.14	1.13–1.15
Hispanic	0.98	0.97–1.00
Other	0.85	0.83–0.87
Metropolitan statistical area		
Neither micropolitan nor metropolitan	0.93	0.92–0.94
Micropolitan	0.91	0.90–0.92
Metropolitan	reference	
Median income of zip code		
<\$33,000	1.10	1.06–1.14
\$33,000–\$39,999	1.02	1.01–1.04
\$40,000–\$49,999	0.97	0.96–0.99
\$50,000–\$62,999	0.97	0.96–0.98
\$63,000	reference	
Percent high school education in zip code		
<60%	1.03	0.94–1.13
60 to <70%	1.03	1.01–1.06
70 to <80 %	1.04	1.02–1.05
80 to <90%	1.04	1.03–1.05
90%	reference	
Chronic condition		
Heart disease (yes vs. no)	1.22	1.20–1.23
Alzheimer's disease/dementia (yes vs. no)	0.83	0.83–0.84
Kidney disease (yes vs. no)	1.27	1.26–1.28
Diabetes (yes vs. no)	1.12	1.11–1.12
Lung disease (yes vs. no)	1.18	1.17–1.19
Depression (yes vs. no)	1.02	1.01–1.03
Stroke (yes vs. no)	1.07	1.06–1.07
Cancer (yes vs. no)	1.11	1.11–1.12