Fragmentation of care in the last year of life: Does dementia status matter?

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Abstract

Background: Care at the end of life is commonly fragmented; however, little is known about commonly used measures of fragmentation of care in the last year of life (LYOL). We sought to understand differences in fragmentation of care by dementia status among seriously ill older adults in the LYOL.

Methods: We analyzed data from adults ≥65 years in the National Health and Aging Trends Study who died and had linked 2011–2017 Medicare fee-for-service claims for ≥12 months before death. We categorized older adults as having serious illness due to dementia (hereafter dementia), non-dementia serious illness or no serious illness. For outpatient fragmentation, we calculated the Bice–Boxerman continuity of care index (COC), which measures care concentration, and the known provider of care index (KPC), which measures the proportion of clinicians who were previously seen. For acute care fragmentation, we divided the number of hospitals and emergency departments visited by the total number of visits. We built separate multivariable quantile regression models for each measure of fragmentation.

Results: Of 1793 older adults, 42% had dementia, 53% non-dementia serious illness and 5% neither. Older adults with dementia had fewer hospitalizations than older adults with non-dementia serious illness but more than older adults without serious illness (mean 1.9 vs 2.3 vs 1, \( p = 0.002 \)). In adjusted models, compared to older adults with non-dementia serious illness, those with
dementia had significantly less fragmented care across all quantiles of COC (range 0.016–0.110) but a lower predicted 90th percentile of KPC, meaning more older adults with dementia had extremely fragmented care on the KPC measure. There was no significant difference in acute care fragmentation.

Conclusions: In the LYOL, older adults with dementia have fewer healthcare encounters and less fragmentation of care by the COC index than older adults with non-dementia serious illness.

KEYWORDS
continuity of care, dementia, end-of-life

INTRODUCTION

End-of-life care is commonly fragmented.\(^1\) Fragmentation of care, refers to care that is scattered across different clinicians and/or health systems, and is defined by being in opposition to continuity of care.\(^2,3\) In the last 6 months of life, the average older adult has at least one healthcare transition (e.g., hospital to skilled nursing facility) and approximately one-third have \(\geq 4\) transitions.\(^4\) Fragmentation of care has been associated with a higher risk of mortality following surgery, higher risk of complications of chronic illness, and higher costs of care; however, few studies focus on fragmentation of care near the end of life despite terminally ill patients and bereaved family members rating continuous, or non-fragmented care, as important to quality of end-of-life care.\(^5–10\)

Although many studies have examined end-of-life fragmentation of care using number of care transitions, less is known about other manifestations of fragmentation of care near the end of life.\(^5,11–13\) Outpatient care can be fragmented because it is spread out across many providers, a concept captured by the continuity of care index, or because the same providers are not seen over time, a concept captured by the known provider of care index.\(^3,14–16\) Limited evidence from studies using the continuity of care index among persons with cancer and end-stage renal disease have found that less fragmented outpatient care is associated with less healthcare use at the end of life; however, little is known about fragmentation of outpatient care among older adults with other serious illnesses at the end of life.\(^17–20\)

In addition to the potential for outpatient fragmentation of care, older adults with serious illness are at risk for multiple hospitalizations near the end of life, and thus may experience acute care fragmentation if they are hospitalized at more than one institution. Interhospital fragmentation is associated with increased risk of mortality, readmission, and longer length of stay.\(^6\) Despite the potential relevance to the seriously ill population, acute care fragmentation, is also not well studied at the end of life.\(^6\)

Serious illness is defined as, “a health condition that carries a high risk of mortality and either negatively impacts a person’s daily function or quality of life, or excessively strains their caregivers.”\(^21\) Previous studies of serious illness have focused on one specific illness, most commonly cancer, or have examined dementia and non-dementia serious illness diagnoses together.\(^22,23\) However, dementia is unique in its care needs.\(^24\) Older adults with dementia experience progressive decline in cognitive and physical function that renders them dependent on others and limits their ability to report symptoms and recall their medical history.\(^25\) Consequently, if an older adult with dementia has fragmented care and sees multiple new clinicians, neither the older adult with dementia nor the clinician may have a complete understanding of the medical history, and the clinician will not have the
context of previous visits and exams to assess new concerns. However, it is unclear if fragmentation of care for seriously ill older adults differs by dementia status, information that is important for refining interventions for the seriously ill population.

In this study, we aimed to determine how fragmentation of care differs among seriously ill older adults by dementia status in the last year of life. We report descriptive statistics of healthcare services use in the last year of life by dementia status, to provide context regarding the volume of different services used. We examine fragmentation of care in the outpatient and acute care (hospital and emergency department [ED]) settings separately.

**METHODS**

**Data source and study population**

We used the National Health and Aging Trends Study (NHATS) linked to 2011–2017 Medicare fee-for-service claims. NHATS is a longitudinal, nationally representative, annual survey of adults age ≥65. Adults in the oldest age groups and Black, non-Hispanic older adults are oversampled. Linked Medicare claims are available for the majority of participants; in this study 64% had linked claims (Figure 1). We limited our study to those who died and had 12 months of continuous claims prior to death. We excluded those who were nursing home dwelling at their initial interview because sample person interviews were not conducted for these older adults. The Johns Hopkins Institutional Review Board approved our study (IRB00161877).

**Measures**

We categorized older adults as having serious illness due to dementia (hereafter dementia), non-dementia serious illness or no serious illness. To identify older adults with dementia, we used the NHATS probable dementia algorithm based on responses at the last interview before death. An individual was considered to have dementia if they or a proxy reported a diagnosis of dementia, if their score on the AD-8 Dementia Screening Interview met a predefined threshold, or if cognitive tests were >1.5 standard deviations from the mean.

Based on validated methods, older adults were considered seriously ill if they had a complex medical condition as identified by ICD-9 or 10 codes (as appropriate for time period) in claims in the last year of life and/or if they had a functional impairment identified in the NHATS survey in the year prior to death. Complex medical conditions (non-dementia serious illness) included 11 conditions (cancer, chronic kidney disease (CKD), chronic obstructive pulmonary disease/interstitial lung disease (COPD/ILD), diabetes, congestive heart failure, hip fracture, neurodegenerative diseases, advanced liver disease, acquired immune deficiency syndrome, stroke, Parkinson’s disease). Each condition had additional criteria for identification to ensure that the condition was serious. For example, CKD had to be stage 5 or
end-stage-renal-disease, and COPD/ILD was only identified if claims indicated that the older adult was using home oxygen or hospitalized for COPD/ILD. A complete list of conditions and criteria are available in Supplemental Table S1. Functional impairment was defined as needing any assistance with one or more of the six activities of daily living (ADLs): eating, bathing, dressing, toileting, transferring, or mobility (getting around inside or getting out of bed).

To operationalize fragmentation of care, we used three measures- two for outpatient care and one for acute care (hospitalization and ED visits). For outpatient care we used ambulatory evaluation and management visits in claims to calculate the Bice–Boxerman continuity of care (COC) index and the known provider of care (KPC) index (Table 1). We selected these two measures since they represent different constructs of continuity of care which may be relevant to seriously ill older adults near the end of life. Since seriously ill older adults are likely to see many different clinicians, we used the COC index to measure how concentrated care is. The COC assesses care as more continuous when a larger share of visits is with fewer different clinicians. In contrast, the KPC index examines whether the older adult maintains the same group of clinicians across two time periods. The KPC index measures care as more continuous when an older adult sees a higher proportion of the same providers over the two time periods. We used claims for the last 12 months of life to calculate both the COC and KPC. For the KPC, we divided the last 12 months of life such that we examined how similar the clinicians were in the first versus last 6 months. For consistency across the concepts measured, we calculated 1-COC and 1-KPC as outcomes to capture the concept of fragmentation of care rather than continuity of care. Fragmentation of acute care was measured by the number of unique hospitals or EDs a patient visited divided by the total number of visits in the last year of life.

Scores for all three fragmentation of care measures ranged from 0 to 1 with higher values representing more fragmentation.

Covariates obtained from the last NHATS interview prior to death included age, sex, race/ethnicity, census region, annual income, highest education, insurance (Medicaid or other supplemental), marital status, self-rated health. Instrumental activity of daily living (iADL) impairment was defined as needing help with household activities such as laundry, meal preparation, grocery shopping, paying bills and handling medications for a health or medical reason. We calculated the Charlson Comorbidity Index based on ICD-9 and 10 codes in claims. We used claims to determine the number of primary care (internal medicine, family medicine, geriatrics,

| **TABLE 1** Description of outcomes measures used to estimate fragmentation of care. |
|---------------------------------|---------------------------------|-----------------|-----------------|
| **Measures**                     | **Construct represented by the measure** | **Formula** | **Examples** |
| Fragmentation of outpatient care | 1-Bice–Boxerman continuity of care index (COC) | Concentration of care among a group of providers over a period of time | \( 1 - \frac{\sum n_i}{n(n-1)} \) | 4 visits to 1 physician  
1-COC = 0  
4 visits split between two physicians  
1-COC = 0.67 |
|                                  | 1-Known provider of care (KPC) | Concentration of care from one time period to the next among a group of providers | Total number of visits in current time period with a clinician also seen in previous time  
\( 1 - \frac{\text{Total number of visits to all physicians in current time period}}{n} \) | 4 visits to 1 clinician who was seen previously  
1-KPC = 0  
4 visits split between 2 clinicians, only 1 seen previously  
1-KPC = 0.5 |
| Acute care fragmentation         | Acute care fragmentation | Dispersion of acute care across institutions | Number of unique hospitals or emergency departments visited  
\( \frac{\text{Total number of hospital and emergency departments visited}}{n} \) | 4 hospitalizations to 1 hospital, acute care fragmentation = 0.25  
4 hospitalizations to 4 hospitals, acute care fragmentation = 1 |

*aAll measures range 0–1 with higher numbers meaning more fragmentation.*
nurse practitioner) and outpatient specialty (all others) visits from evaluation and management codes, number of hospitalizations, ED visits, post-acute care skilled nursing facility use and hospice use in the last year of life.

Analysis

We built three cohorts for analysis, one for each outcome measure. To ensure reliable estimates, we limited our analysis for COC and KPC to those with ≥3 outpatient visits in the last 12 or 6 months of life, respectively.\textsuperscript{28,31} Similarly for acute care fragmentation, we limited our analysis to those with ≥3 hospitalizations or ED visits in the last year of life.\textsuperscript{29} For the acute care analysis, once we applied these criteria, the sample size for not seriously ill older adults was small (n = 7) so we limited our comparison to those with dementia or a non-dementia serious illness.

Descriptive statistics of characteristics of older adults are presented as means and standard deviations (SDs) or medians and interquartile ranges (IQR), as appropriate for continuous variables, and frequencies for categorical variables. Comparison of characteristics between groups were assessed using chi-square test for categorical variables, and ANOVA or nonparametric Wilcoxon test, as appropriate for continuous variables.

The measures of fragmentation did not satisfy the ordinary least squares regression assumptions of normal and homoscedastic residuals, so we used nonparametric quantile regression models that do not rely on these assumptions to examine associations between groups (having no serious illness, non-dementia serious illness, or dementia) and the outcomes of interest for the 10th, 25th, 50th, 75th, 90th quantiles of the distribution separately. The quantile regression model tells us the difference in predicted percentile cut points on the fragmentation measures between the groups being compared (reference = non-dementia serious illness). For example, in a model examining 1-COC for the 50th quantile (median), a significant coefficient with a value of 0.2 for those with dementia would mean that the estimated median of 1-COC is 0.2 points greater for older adults with dementia than the estimated median of 1-COC for older adults with non-dementia serious illness. Covariates for the multivariable models were selected based on a conceptual model of treatment intensity for seriously ill persons, the Andersen model of health behavior and literature review (Supplemental Figure S1).\textsuperscript{32,33} Final models were adjusted for age, sex, race/ethnicity, insurance, Charlson comorbidity score, ADL impairment, whether an older adult attended medical visits alone, number of days spent in the hospital (outpatient fragmentation models only), and census region. Given differential enrollment in hospice across serious illness groups and the potential for hospice enrollment to influence measurement of fragmentation of care, we conducted a sensitivity analysis stratifying our analysis by hospice enrollment. All analyses were performed using SAS 9.4 (SAS Institute Inc., Cary, NC).

RESULTS

We identified a population of 1793 older adults who died and met our inclusion criteria (Figure 1). Only 5% (n = 85) were not seriously ill. Of the 1708 remaining older adults, 44% (n = 760) had dementia. Descriptive characteristics of the three samples are provided by serious illness category in Table 2 and by outcome cohort in Supplemental Table S2.

In the last year of life, older adults with dementia had fewer ED visits, hospitalizations and outpatient specialty visits than older adults with non-dementia serious illness, but higher utilization of these services than older adults with no serious illness (Figure 2). Mean hospital length of stay was longest for older adults with non-dementia serious illness, followed by those with dementia and shortest for older adults who were not seriously ill (7.3 vs 5.7 vs 4 days, \( p < 0.001 \)). Older adults with dementia were more likely to use hospice (58% vs 21% vs 48%, \( p < 0.001 \)) or have a post-acute skilled nursing facility stay (19% vs 9% vs 16%, \( p < 0.001 \)) than older adults with no serious illness or a non-dementia serious illness.

In unadjusted and adjusted analyses using COC, older adults with dementia had less fragmentation of care than older adults who were seriously ill without dementia (Figure 3). The difference in fragmentation of care between older adults with dementia and those with non-dementia serious illness was greatest for those with least fragmented care and smallest for those with the most fragmented care (−0.109 10th percentile \( p = 0.007, \) −0.016 90th percentile \( p = 0.04 \)). The estimated median of fragmentation was lower for older adults with no serious illness than for older adults with non-dementia serious illness (−0.086, \( p = 0.02 \)) (Supplemental Table S3).

No significant difference in fragmentation of care was found using KPC in unadjusted analyses. In adjusted analyses, older adults with dementia had more fragmented care on the predicted 90th percentile cut point than older adults with non-dementia serious illness (estimated difference 0.085, \( p = 0.002 \)) (Supplemental Table S4); meaning that when comparing the 10% of persons with the most fragmented care in each group, older adults with dementia had significantly worse fragmentation. There was no significant difference for any other quantile in adjusted analyses or when comparing older adults with...
TABLE 2 Characteristics of older adults 65 years and older in the last year of life from the National Health and Aging Trends Study linked to Medicare Fee-for-Service Claims, 2011–2017

| Variable                        | Not seriously ill, no dementia (N = 85) | Seriously ill without dementia (N = 948) | Dementia (N = 760) | Global test | Seriously ill without dementia Ref: Dementia | Not seriously ill, no dementia Ref: Dementia |
|--------------------------------|----------------------------------------|----------------------------------------|-------------------|-------------|---------------------------------|---------------------------------|
| Age, mean (SD)                 | 82.2 (8.19)                            | 82.9 (7.88)                            | 87.5 (7.44)       | <0.001      | <0.001                          | 0.72                            |
| Female                         | 42 (49%)                               | 493 (52%)                              | 460 (61%)         | 0.001       | <0.001                          | 0.65                            |
| Race/ethnicity                 |                                        |                                        |                   |             |                                 |                                 |
| White, non-Hispanic            | 69 (84%)                               | 720 (77%)                              | 507 (68%)         | <0.001      | <0.001                          | 0.53                            |
| Black, non-Hispanic            | 10 (12%)                               | 154 (17%)                              | 184 (25%)         |             |                                 |                                 |
| Other (Am Indian/Asian)        | 1 (1%)                                 | 24 (3%)                                | 16 (2%)           |             |                                 |                                 |
| Hispanic                       | 2 (2%)                                 | 35 (4%)                                | 41 (5%)           |             |                                 |                                 |
| Highest education              |                                        |                                        |                   |             |                                 |                                 |
| <High school grad              | 13 (16%)                               | 255 (27%)                              | 290 (39%)         | <0.001      | <0.001                          | 0.070                           |
| High school grad               | 30 (37%)                               | 269 (29%)                              | 207 (28%)         |             |                                 |                                 |
| Beyond high school             | 39 (48%)                               | 414 (44%)                              | 246 (33%)         |             |                                 |                                 |
| Annual income                  |                                        |                                        |                   |             |                                 |                                 |
| <$15,000                       | 26 (31%)                               | 349 (37%)                              | 381 (50%)         | <0.001      | <0.001                          | 0.39                            |
| $15,000–$29,999                | 20 (24%)                               | 249 (26%)                              | 190 (25%)         |             |                                 |                                 |
| $30,000–$59,999                | 25 (29%)                               | 209 (22%)                              | 124 (16%)         |             |                                 |                                 |
| ≥$60,000                       | 14 (16%)                               | 141 (15%)                              | 65 (9%)           |             |                                 |                                 |
| Insurance                      |                                        |                                        |                   |             |                                 |                                 |
| Medicaid                       | 6 (7%)                                 | 183 (20%)                              | 236 (32%)         | <0.001      | <0.001                          | 0.001                           |
| Has supplemental insurance     | 57 (70%)                               | 624 (67%)                              | 434 (58%)         | 0.001       | <0.001                          | 0.63                            |
| Proxy respondent               | 38 (45%)                               | 647 (68%)                              | 669 (88%)         | <0.001      | <0.001                          | <0.001                          |
| Marital status                 |                                        |                                        |                   |             |                                 |                                 |
| Married/living with a partner  | 34 (40%)                               | 388 (41%)                              | 219 (29%)         | <0.001      | <0.001                          | 0.99                            |
| Separated/divorced             | 10 (12%)                               | 110 (12%)                              | 65 (9%)           |             |                                 |                                 |
| Widowed/never married          | 41 (48%)                               | 450 (47%)                              | 472 (62%)         |             |                                 |                                 |
| Self-rated very good/excellent health | 69 (81%)                           | 473 (50%)                              | 318 (42%)         | <0.001      | <0.001                          | <0.001                          |
| Census division                |                                        |                                        |                   |             |                                 |                                 |
| Northeast Region               | 15 (19%)                               | 160 (19%)                              | 125 (19%)         | 0.04        | <0.01                           | 0.99                            |
| Midwest Region                 | 21 (27%)                               | 223 (26%)                              | 131 (20%)         |             |                                 |                                 |
| South Region                   | 28 (36%)                               | 319 (38%)                              | 302 (45%)         |             |                                 |                                 |
| West Region                    | 14 (18%)                               | 141 (17%)                              | 112 (17%)         |             |                                 |                                 |
| ADL impairment                 | 5 (6%)                                 | 785 (83%)                              | 723 (95%)         | <0.001      | <0.001                          | <0.001                          |
| IADL impairment                | 15 (18%)                               | 582 (61%)                              | 682 (90%)         | <0.001      | <0.001                          | <0.001                          |
| If seen the regular doctor last year, went to doctor alone | 60 (76%) | 388 (43%) | 46 (6%) | <0.001 | <0.001 | <0.001 |
| Charlson index, mean (SD)      | 1.6 (1.85)                             | 3.6 (3.91)                             | 2.7 (3.01)        | <0.001      | 0.002                           | <0.001                          |
| Hospice use                    | 18 (21%)                               | 453 (48%)                              | 440 (58%)         | <0.001      | <0.001                          | <0.001                          |
(Continues)
dementia to those with no serious illness. There was no significant difference in acute care fragmentation in unadjusted or adjusted analyses (Supplemental Table S5).

In a sensitivity analysis, stratified by hospice enrollment, we found similar estimated differences in COC but had fewer statistically significant findings due to loss in power (Supplemental Table S6).

**DISCUSSION**

We found that in comparison to older adults with non-dementia serious illness, older adults with dementia had lower utilization of most healthcare services in the last year of life and less fragmented care as measured by the COC index. We did not find consistent differences in fragmentation of care using the KPC or acute care fragmentation indices between those with dementia and those with non-dementia serious illness, or by any measure examined between older adults without serious illness and those with a non-dementia serious illness. Our results indicate that the healthcare ecosystem for older adults with dementia may be smaller than that for older adults with non-dementia serious illness at the end of life.

The results of this study provide a more comprehensive view of fragmentation of healthcare use among older adults with serious illness and dementia.
adults in the last year of life than has been previously described. Previous studies on fragmentation of care near the end of life have focused primarily on transitions of care and have demonstrated that older adults with dementia have a lower number of transitions, hospitalizations and intensive care unit (ICU) stays in the last 90 days of life than older adults who died of cancer or chronic obstructive pulmonary disease. The results of our study similarly demonstrate that older adults with dementia have fewer hospitalizations than their counterparts with non-dementia serious illness, and we add that the burden of outpatient visits to both primary and specialty care is lower for older adults with dementia compared to older adults with non-dementia serious illness and older adults without serious illness. Further, the difference in fragmentation of care we observed in our analysis using the COC index adds that outpatient care for older adults with dementia is more concentrated among a group of providers than care for older adults who are seriously ill without dementia. In sum, older adults with dementia have fewer healthcare encounters and a smaller group of healthcare professionals involved in care in the last year of life than older adults with a non-dementia serious illness.

Observed differences in fragmentation of care by dementia status using the KPC index indicate that some older adults with dementia may be at risk for seeing a high proportion of “new” providers, potentially creating challenges for coordination of care. However, given the lack of consistent findings across quantiles for the KPC measure and the large number of comparisons made in the study, this finding may be due to chance.

The different results we found for fragmentation of outpatient care are likely because the COC and KPC indices use different constructs to operationalize fragmentation of care. Others who have used both indices have similarly found different results. Further, because COC and KPC represent different constructs, we had to use different time periods to calculate these measures. The difference in time period examined and the associated difference in sample size for the two measures may also explain some of the difference in our results.

There was no significant difference in acute care fragmentation by dementia status in this study. This could be related to the low sample size for this analysis as we had to limit inclusion to those with three or more hospitalizations or ED visits. Future studies with a larger total sample size could further examine this issue.

There are several limitations to our study. First, we use claims-based measures to estimate fragmentation of care. These measures do not necessarily reflect the patient and family perspective and our results do not address whether the decreased fragmentation of care we observed among older adults with dementia resulted in better care. Since end-of-life care is often improved by additional team members (e.g., palliative medicine clinicians) future work is needed to determine what level of fragmentation of care is ideal near the end of life. Second, we limited our analysis to older adults with fee-for-service Medicare, and so our findings may not be
generalizable to older adults with Medicare Advantage. Third, due to restrictions in our data use agreement to maintain the confidentiality of older adults in our data set, we were only able to adjust for census region and not a more precise measure of geography which may reflect local practice and referral patterns and access to care.

In sum, in the last year of life, older adults with dementia had lower utilization of most healthcare services and have less fragmented care as measured by the COC than their counterparts with non-dementia serious illness. More research is needed to understand the consequences of fragmentation of care in the last year of life on care quality and the end-of-life care experience from the perspective of older adults and families.

CONFLICT OF INTEREST
Dr. Cynthia Boyd acknowledges receiving royalties from UptoDate and Dynamed.

AUTHOR CONTRIBUTIONS
Conception and design: Stephanie Nothelle, Talan Zhang, David Roth, Jennifer Wolff, Cynthia Boyd, Amy Kelley. Analysis and interpretation of data: Stephanie Nothelle, Talan Zhang, David Roth, Jennifer Wolff, Cynthia Boyd, Amy Kelley. Drafting and revising the article: Stephanie Nothelle, Talan Zhang, David Roth, Jennifer Wolff, Cynthia Boyd, Amy Kelley. Final approval of the manuscript: Stephanie Nothelle, Talan Zhang, David Roth, Jennifer Wolff, Cynthia Boyd, Amy Kelley. The authors wish to acknowledge Shang-En Chung, ScM for her contributions to statistical analysis early in the project.

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