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Prevalence of co-occurring serious illness diagnoses and association with health care utilization at the end of life

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Abstract

Introduction: End-of-life care differs by serious illness diagnosis. Cancer and dementia are serious illnesses that have been associated with less intensive end-of-life health care use. It is not known how health care utilization varies in the presence of >1 serious illness.

Methods: We used the Rochester Epidemiology Project to identify persons living in a midwestern area who died on July 1, 2017–June 30, 2018 at age ≥65 years, and were seriously ill. We examined the number of emergency department (ED), hospital, and intensive care unit (ICU) stays in the last 6 months and the last 30 days of life. We used Poisson regression to determine the incidence rate ratio for ED, hospital, and ICU stay in the last 6 months and 30 days of life by number of serious illness diagnoses. For cancer and dementia, we examined the effect of an additional serious illness.

Results: We included a population of 1372 adults who were, on average, 84 years, 52% female, and 96% white. Approximately 41% had multiple serious illnesses. Compared to older adults with 1 serious illness diagnosis, rates of hospitalization, and ICU stay for adults with 2 or ≥3 serious illness diagnoses were at least 1.5 times higher in the last 6 months and the last 30 days of life. Rates of ED visits were significantly higher for older adults with 2 or ≥3 serious illness diagnoses in the last 6 months of life, but only higher for those with ≥3 versus 1 serious illness diagnosis in the last 30 days of life. For both cancer and dementia, rates of ED visits, hospitalization and ICU stay were lower for the condition alone than when an additional serious illness diagnosis was present.

Conclusion: Having multiple serious illnesses increases the risk of health care utilization at the end of life.

KEYWORDS
end-of-life, health care utilization, serious illness

INTRODUCTION

Improving care for seriously ill older adults is a national health priority.[1] Serious illness is defined as a condition with a high risk of mortality that negatively impacts quality of life, daily function, or excessively strains caregivers.[2] Seriously ill older adults are among the most frequent users of health care services and contribute disproportionately to rising Medicare spending.[3–5] They are at high risk for poor symptom control, low patient and family satisfaction, and care that may not be consistent with personal wishes.[6–12]

Serious illness often precedes death and is heterogenous. In older adults, serious illness encompasses dementia, functional impairment, and other advanced medical illnesses like end-stage renal disease and metastatic cancer. Limited evidence on end-of-life care for seriously ill older adults suggests that quality and intensity of care at the end of life varies across different illness types.[9,13] Compared to older adults who die of cancer or dementia, older adults with serious illness due to other diagnoses (e.g., end-stage renal disease) are significantly less likely to enroll in hospice or die at home, and have lower family reported end-of-life quality of care.[9,13] Although it is unclear why these differences exist, some hypothesize that the gradual decline in physical function and health that often occurs with serious illnesses like cancer and dementia better prime the clinician, patient, and family to think about and discuss end-of-life care, than in other conditions.[13]

Older adults with dementia, cancer, and other serious illnesses may have multiple diagnoses that on their own would be severe enough to be considered a serious illness. It is unclear how often older adults have multiple serious illnesses and how the presence of another serious illness diagnosis may influence end-of-life health care utilization. Studies of multiple chronic conditions have shown that increasing numbers of chronic conditions are associated with increasing health care utilization near the end-of-life.[14,15] Based on these findings, having multiple serious illness diagnoses is likely to also increase the risk of health care utilization. However, we hypothesize that multiple serious illness diagnoses may also result in clinician, patient, and family awareness of poor prognosis, stimulating conversations about palliative approaches to care and resulting in reduced acute care use at the end of life. Understanding how multiple serious illness diagnoses influences health care utilization is important for planning interventions aimed at improving end-of-life care and at lowering health care costs for older adults with serious illness.

Key points

- In the last year of life, >1 serious illness diagnosis is common (41% in this study).
- >1 serious illness diagnosis is associated with increased health care use near the end of life.

Why does this paper matter?

Understanding seriously ill older adults end-of-life health care use is important for designing interventions aimed at improving care for this high-risk population.

To address these questions, we examined differences in health care utilization during two end-of-life time periods (6 months and 30 days prior to death) among seriously ill older adults. We specifically aimed to describe how emergency department (ED), hospital, and intensive care unit (ICU) visits differ when an older adult has multiple serious illness diagnoses. Given the previously noted differences in end-of-life care for those with dementia and cancer, we also examined how ED, hospital, and ICU visits for older adults with dementia and cancer differed in the presence of another serious illness diagnosis near the end of life.[13]

METHODS

In this death follow-back study, we identified persons from southeastern Minnesota who died between July 1, 2017 and June 30, 2018 at the ≥65 years and using the Rochester Epidemiology Project (REP). The REP has been described in detail elsewhere.[16] Briefly, the REP is a medical records-linkage system that captures health care information from a consortium of local healthcare providers, and mortality data from the State of Minnesota. We studied persons living in a 7-county region with high population capture. The REP includes medical records data from 93.8% of the population residing in this region. Persons included provided research authorization to use their records for medical research. This study was approved by the Mayo Clinic and Olmsted Medical Center Institutional Review Boards.

TABLE 1 Characteristics of older adults (age ≥65) who were seriously Ill prior to death in the Rochester epidemiology project study, July 2017–June 2018

Characteristic	*n*, % *n* = 1372
Age (median, [Q1, Q3])	83.6 (76.4,89.8)
Female sex	713, 52.0
Race	
White	1319, 96.1
Black	8, 0.6
Asian	24, 1.8
Other	21, 1.5
Non-hispanic ethnicity	1361, 99.2
Education	
High school degree or less	708, 51.6
Some college or college degree	375, 27.3
Advanced degree	140, 10.2
Unknown	149, 10.9
Marital status	
Single/Widowed/Divorced	740, 53.9
Married/Living together	615, 44.8
Unknown	17, 1.2
Urban residence	713, 52.0
Serious illness diagnoses	
Cancer	439, 32.0
Renal Failure	150, 10.9
Dementia	357, 26.0
Liver Disease	47, 3.4
Diabetes	320, 23.3
ALS/Parkinson	29, 2.1
AIDS	0
Hip Fracture	106, 7.7
COPD	324, 23.6
CHF	358, 26.1
Stroke	38, 2.8
Activity of daily living (ADL) impairment	
Eating	55, 4.0
Bathing	274, 20.0
Dressing	212, 15.5
Toileting	140, 10.2
Transferring	153, 11.2
Walking	324, 23.6
Any ADL	415, 30.3
Number of serious illness diagnoses	
0	0
1	812, 59.2
2	373, 27.2
3	145, 10.6
4	42, 3.3

(Continues)

TABLE 2 Distribution of serious illness diagnoses and number and proportion with a second serious illness diagnosis by diagnosis among older adults in the Rochester epidemiology project who died and were age ≥65 at death

Condition[a]	No other serious illness *n*,%	At least one other serious illness *n*,%
Cancer	271, 61.7	168, 38.3
Renal failure	28, 18.7	122, 81.3
Dementia	236, 66.1	121, 33.9
Liver disease	12, 25.5	35, 74.5
Diabetes	90, 28.1	230, 71.9
ALS/Parkinson	14, 48.3	15, 51.7
Hip fracture	32, 30.2	74, 69.8
COPD/ILD	47, 14.5	277, 85.5
CHF	64, 17.9	294, 82.1
Stroke with hospitalization	18, 47.4	20, 52.6

Abbreviations: ALS, amyotrophic lateral sclerosis; CHF, congestive heart failure; COPD/ILD, chronic obstructive pulmonary disease/interstitial lung disease.

[a]There were zero persons identified with AIDS.

We electronically searched the REP indices for persons who met published criteria for serious illness.[17] Older adults were considered seriously ill if they met the criteria for one of the following 10 serious illness diagnoses identified by ICD-10 codes: (1) cancer, poor prognosis and metastatic; (2) dementia; (3) chronic kidney disease stage 5 and end-stage renal disease (ESRD); (4) chronic obstructive pulmonary disease or interstitial lung disease (COPD/ILD), only if using home oxygen or hospitalized for the condition; (5) diabetes, only if severe complications (ischemic heart disease, peripheral vascular disease, renal failure); (6) congestive heart failure (CHF), only if using home oxygen or hospitalized for the condition; (7) hip fracture; (8) neurodegenerative disease (e.g., amyotrophic lateral sclerosis); (9) advanced liver disease or cirrhosis; (10) acquired immune deficiency syndrome (AIDS). In a supplemental analysis, we also included functional impairment (needs assistance with 1+ activities of daily living [ADL] including bathing, eating,

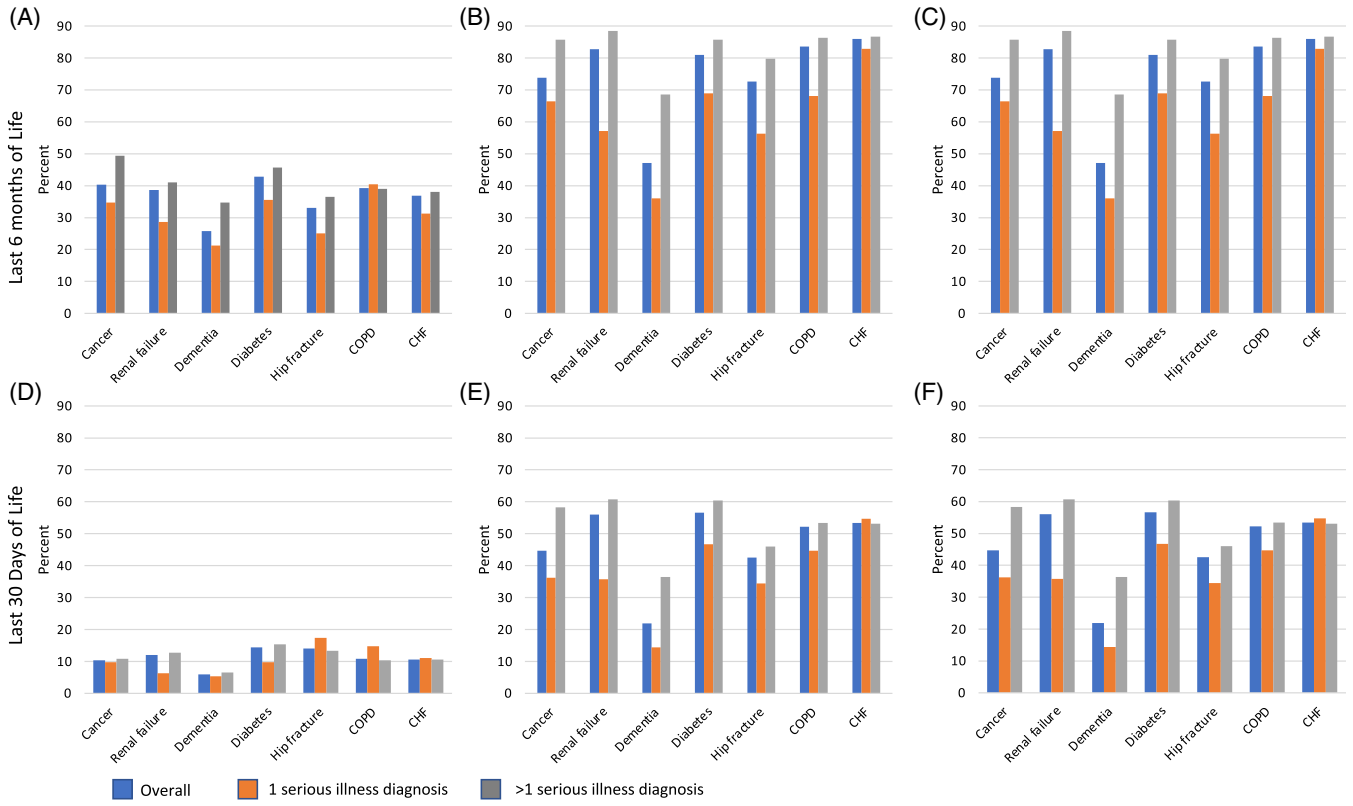

FIGURE 1 Proportion of seriously Ill older adults who had at least one Emergency Department, Hospital or Intensive Care Unit stay in the last 6 months or 30 days of life by serious illness diagnosis and number of serious illness diagnoses. Percent of adults who died and were at least 65 years or older with at least one emergency department (Panels A and D), hospital (Panels B and E) or intensive care unit (Panels C and F) visit in the last 6 months (Panels A–C) or the last 30 days (Panels D–F) of life. Percent utilization is displayed by serious illness diagnosis with three categories per diagnosis: overall (blue), 1 serious illness diagnosis (orange) or >1 serious illness diagnosis (gray). CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease

dressing, toileting, transferring or walking) as a serious illness diagnosis. For the 10 diagnoses listed, we required at least one ICD-10 code in the last year of life. For functional impairment, we examined patient responses to questions about activities of daily living from a clinical intake form completed in the 2 years prior to death. Categories were not mutually exclusive (i.e., older adults could have multiple serious illness diagnoses).

ED, hospitalization and ICU visits for any cause were extracted for 6 months before death and for 30 days before death. We chose to examine the last 6 months of life because hospice eligibility is defined by a 6 month or less prognosis. However, we chose to also examine the last 30 days of life because a shorter time period may be more realistic for patients and clinicians to shift toward a less aggressive approach to care. ED visits that resulted in a hospitalization were counted as a hospitalization. In-hospital transfers or transfers between hospitals were counted as a single hospitalization. Due to small sample size ($n < 50$) we do not report utilization for persons with liver disease, ALS/Parkinson's, strokes, or AIDS separately; however, persons with these diagnoses were retained in the analytic cohort.

Descriptive characteristics of the population were summarized overall, including the number of serious illness diagnoses and for functional impairment, the number of ADL domains impaired. For each serious illness diagnosis, we summarized the overall number of occurrences, the number of occurrences of the diagnosis alone, and the number of times the diagnosis co-occurred with another diagnosis. Poisson regression was used to examine the association of cancer and dementia with ED visits, hospitalizations, and ICU visits in the last 6 months and 30 days of life. Persons with a diagnosis of cancer alone (referent group) were compared with persons with one noncancer diagnosis, more than one non-cancer diagnosis, and to persons with cancer plus other serious illness diagnoses. Similarly, persons with a diagnosis of dementia alone (referent group), were compared to persons with one nondementia diagnosis, more than one nondementia diagnosis, and to persons with dementia plus other serious illness diagnoses. Poisson regression models were used to examine the association of the number of serious illness diagnoses with ED visits, hospitalizations, and ICU visits. Persons with one serious illness diagnosis were considered the referent group.

Results are presented graphically as incidence rate ratios (IRR) and 95% confidence intervals.

Functional impairment on its own is often considered a manifestation of serious illness.[4] However, we did not include ADL impairment as a serious illness diagnosis in the main analysis because impairment in ADLs in the presence of another serious illness may represent worsening of that single condition to the point of functional impairment rather than two serious illnesses. However, including functional impairment as a serious illness diagnosis captures older adults who might otherwise be missed because they are seriously ill from multiple chronic conditions rather than a single, driving diagnosis. Further, including functional impairment as a possible second diagnosis also allows for identification of older adults who not only have a serious illness diagnosis but are so ill that they are functionally impaired. Therefore, we completed a supplemental analysis in which we did count functional impairment as a serious illness diagnosis.

RESULTS

We included a population of 1372 adults ≥65 years who had a serious illness and died. Included persons were, on average, 84 years old, 52% female, and 96% white. Most had a high school education or less (52%), were single or widowed (54%), and lived in an urban area (52%) (Table 1). The most common serious illness diagnoses were metastatic or poor prognosis cancer (32%), dementia (26%), CHF (26%), COPD/ILD (24%), and diabetes with complications (23%). Approximately 30% of the population had impairment in at least one ADL, most commonly difficulty with walking or climbing stairs (24%).

Approximately 40% of included older adults met criteria for multiple serious illness diagnoses. Although the vast majority of older adults with ESRD (81%), CHF (82%), or COPD/ILD (85%) had at least one other serious illness diagnosis, approximately one-third of older adults with dementia (34%) and cancer (38%) had a second serious illness diagnosis (Table 2).

In the last 6 months of life, 35% of seriously ill older adults had at least one ED visit, 69% at least one hospitalization and 29% at least one ICU stay. In the last 30 days of life, 10% of seriously ill older adults had at least one ED visit, 41% at least one hospitalization, and 18% at least one ICU stay. Older adults with dementia had the lowest proportion of at least one ED visit, hospitalization or ICU stay in both the last 6 months and the last 30 days of life (Figure 1). In comparison, unadjusted utilization for

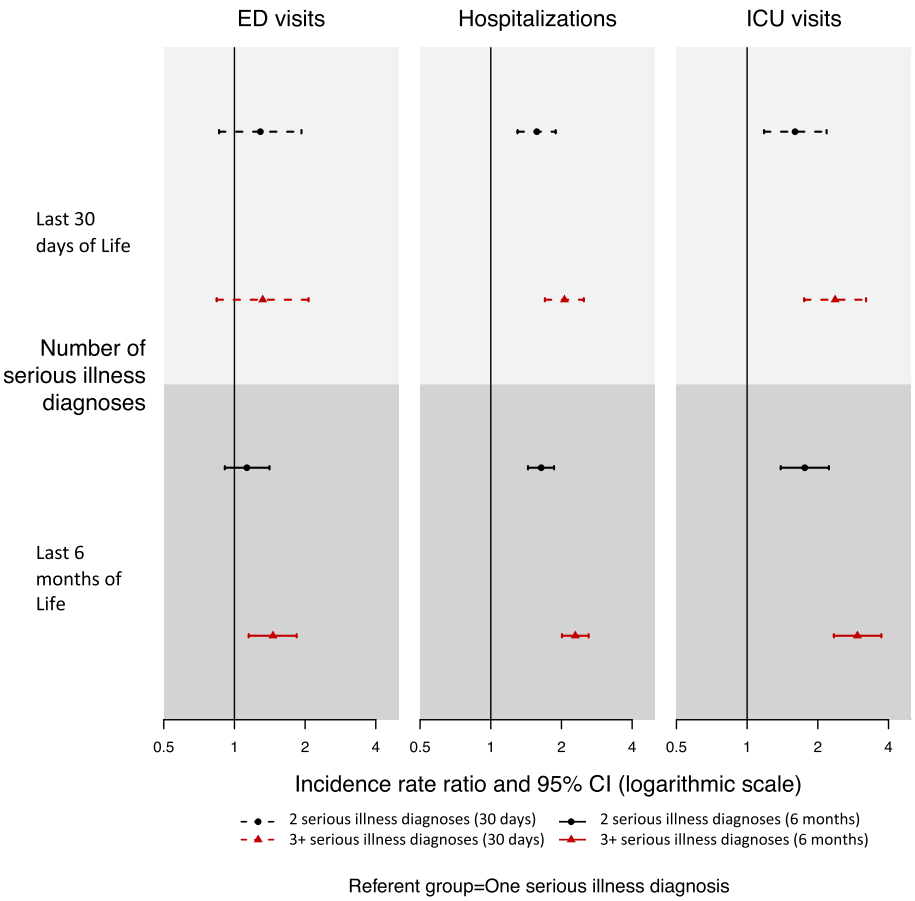

FIGURE 2 Adjusted incidence rate ratios for Emergency Department (ED), Hospital and Intensive Care Unit (ICU) visits in the last 6 months and 30 days of life by number of serious illness diagnoses. Adjusted IRR for older adults who died and were at least 65 years old for three types of health service utilization: emergency department, hospitalization and intensive care unit stay. IRR are for two time periods: the last 30 days of life (dashed line error bars, light gray background) and 6 months of life (solid error bars, darker gray background) and compare those with 2 and those with 3 or more serious illness diagnoses with those who have 1 serious illness diagnosis

older adults with cancer was similar to older adults with other serious illness diagnoses. For almost all conditions, having a second serious illness increased the proportion of older adults with each type of healthcare utilization.

In adjusted analyses, compared to older adults with one serious illness diagnosis, rates of ED visits were 1.28 (95% CI, 1.02–1.60) times higher for older adults with two serious illness diagnoses and 1.84 (95% CI, 1.41–2.40) times higher for older adults with ≥3 serious illness diagnoses in the last 6 months of life. (Figure 2) For older adults with ≥3 serious illness diagnoses, but not older adults with two diagnoses, rates of ED visits remained significantly higher than for older adults with one serious illness diagnosis (1.66, 95% CI 1.01–2.74) in the last 30 days of life. Rates of hospitalization and ICU stays increased with increasing number of serious illness diagnoses in both the last 6 months and the last 30 days of life.

Among older adults with cancer, a second serious illness diagnosis increased the rate of ED visits in the last 6 months but not in the last 30 days of life. (Figure 3) In addition, older adults with cancer plus a second serious illness had rates of hospitalization and ICU stay that were >1.5 times higher than that of older adults with cancer alone. Compared to older adults with cancer alone, those with one noncancer diagnosis had lower

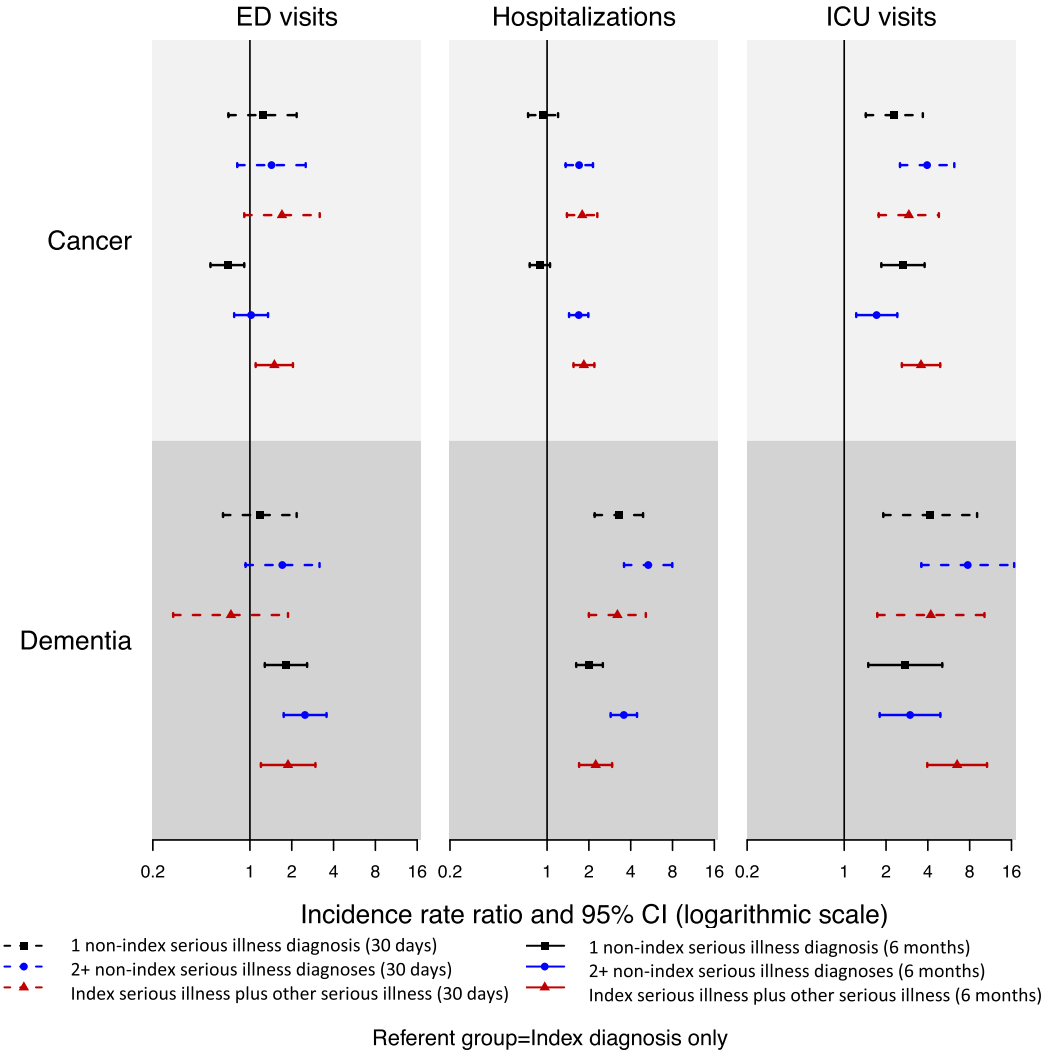

FIGURE 3 Adjusted incidence rate ratios for Emergency Department (ED), Hospital and Intensive Care Unit (ICU) visits in the last 6 months and 30 days of life for older adults with cancer and dementia. Adjusted IRR for older adults with cancer or dementia who died and were at least 65 years old for three types of health service utilization: emergency department, hospitalization, and intensive care unit stay. IRR are for two time periods: the last 30 days of life (dashed line error bars) and 6 months of life (solid error bars) and compare those with any single non-cancer or dementia diagnosis (black), two or more non-cancer or non-dementia diagnoses (blue) and those with cancer or dementia and an additional serious illness diagnosis (red) to those with only cancer or dementia diagnoses (referent group). Index condition refers to either dementia or cancer, as indicated by the labels along the y-axis

rates of ED visits in the last 6 months of life but higher rates of ICU stay in the last 6 months and the last 30 days of life. Older adults with two noncancer diagnoses had higher rates of hospitalization and ICU stay than older adults with cancer alone in the last 6 months and the last 30 days of life.

Among older adults with dementia, a second serious illness was associated with an increased rate of ED visits in the last 6 months, and hospitalizations and ICU stays in the last 6 months and the last 30 days of life (Figure 3). Compared to older adults with dementia as their only serious illness, older adults with one or more nondementia serious illness had at least 1.8 times the rate of ED visits, hospitalizations and ICU stays in the last 6 months and the last 30 days of life, with the exception of ED visits in the last 30 days of life.

Supplemental analyses which include functional impairment as a serious illness diagnosis resulted in identification of 83 additional older adults who were seriously ill. However, descriptive statistics of the cohort and unadjusted and adjusted analyses of healthcare utilization did not differ significantly from our main analysis (Data S1).

DISCUSSION

We report that approximately 41% of older adults at the end of life had multiple serious illness diagnoses. Increasing numbers of serious illness diagnoses increased the risk of healthcare utilization near the end of life; however, rates of utilization differed by type of serious illness. Older adults with dementia or cancer had lower rates of hospitalization and ICU stay near the end of life than older adults with other serious illness diagnoses. Our results show a high burden of multiple advanced illnesses among seriously ill older adults at the end of life, and highlight differences in healthcare utilization by number and type of serious illness diagnosis.

Although many studies report the prevalence of multiple chronic conditions at the end of life, we provide new evidence about the presence of multiple serious illness diagnoses, conditions, which on their own, are severe enough to warrant consideration of a palliative approach to care.[2] The vast majority of older adults with COPD, end-stage renal disease and CHF in this study had a second serious illness diagnosis at the end of life, whereas those with dementia had a second serious illness diagnosis less than half of the time. These differences may reflect differences in the pathophysiology of various disease processes. For example, CHF may lead to poor organ perfusion and end-stage renal disease. In contrast, the pathophysiology of a neurodegenerative condition like dementia is less likely to directly result in organ failure. The relatively high prevalence of multiple serious illness diagnoses indicates that end-of-life interventions aimed at older adults with serious illness should take a symptom and need based approach to care rather than a single-disease focused approach.

We provide novel evidence about the impact of co-occurring serious illness diagnoses on end-of-life care. We had considered that the presence of multiple serious illness diagnoses might be more likely to prompt the clinician and patient to discuss end-of-life care and potentially reduce hospitalization and ICU use. However, even in the last 30 days of life, we report a positive association between number of serious illness diagnoses and healthcare use. A possible explanation for increased utilization in the setting of an increased number of serious illness diagnoses is that care for these individuals may be episodic and fragmented across different providers.[18] Each visit may be focused on the current acute issue, rather than reflecting the larger picture of the person's care priorities and prognosis.[19–21] Maintaining a long term, continuous relationship with a primary care clinician, who is perhaps better poised than a specialist to focus on the whole person rather than on a single disease, may be particularly important for older adults with multiple serious illnesses.

Consistent with other studies, we observed that patients with cancer and dementia have less intense healthcare use at the end-of-life compared to patients with other serious illness diagnoses.[13] For older adults with cancer, however, the lower rates of healthcare use only applied to ICU stays and not hospitalization or ED visits. We add new evidence that older adults with cancer or dementia at the end of life are less likely to have another serious illness diagnosis; however, when an additional serious illness diagnosis is present, the rate of healthcare utilization is similar to persons with non-dementia or non-cancer diagnoses. These findings suggest that the additional serious illness diagnosis may drive utilization. Additional research is needed to determine how a second serious illness diagnosis influences end-of-life care discussions and patient and family decision-making about goals of care in the context of cancer or dementia. Future studies could also examine the association of other combinations of serious illness diagnoses on utilization.

Our supplemental analysis including functional impairment as a criterion for serious illness, did not add a significant number of individuals and did not change overall inferences. This may suggest that among seriously ill older adults at the end-of-life, functional impairment is pervasive and may not be a sensitive indicator of differences in acute care utilization across groups.

There are several limitations to our study. We identified all of the serious illness diagnoses using ICD codes, which are known to be imperfect and may have resulted in misclassification of some diseases (e.g., dementia).[22]

The data used in this study come from one geographic region of the United States and thus may not be generalizable to other parts of the country or of the world. Our sample is predominantly white race, which, is a further limitation, considering the known racial disparities in healthcare utilization at the end of life. The characteristics of this population are similar to those of persons residing in the US Upper Midwest; however, no single region can fully represent all other regions, and additional studies are necessary to understand the impact of local care decisions on end-of-life utilization.[16] On the other hand, a strength of the data used is the near total capture of residents in the included geographic region, which reduces the risk of selection bias. We identified limitations in ADLs from a patient or proxy questionnaires completed annually at primary care visits, and responses were carried forward from the prior year if the questionnaire was missing in the year of death. We thus may have considered older adults as less impaired than they truly were.

In summary, having multiple serious illness diagnoses is common at the end of life and increases the risk of end-of-life healthcare utilization. Our results confirm that patterns of healthcare use near the end of life are lower for dementia patients overall, but only lower in reference to rates of ICU stay for older adults with cancer. However, for both cancer and dementia, an additional serious illness diagnosis increased the risk of utilization near the end of life to be more similar to the utilization observed in persons with other serious illness diagnoses. Older adults with multiple serious illness diagnoses may benefit from interventions focused on discussing care priorities.

AUTHOR CONTRIBUTIONS

Conception and design of study (Stephanie Nothelle, Alanna M. Chamberlain, Debra Jacobson, Cynthia M. Boyd, Jennifer L. St. Sauver), analysis (Debra Jacobson, Chun Fan) and interpretation of data (all), drafting manuscript (Stephanie Nothelle, Debra Jacobson, Jennifer L. St. Sauver), revising manuscript (all), final approval of version to be published (all).

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CONFLICT OF INTEREST

Dr. Boyd reports receiving royalties from UptoDate and DynaMed.

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The sponsor did not have a role in the design, methods, analysis or preparation of the paper.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

Data S1 Results of supplemental analysis including functional impairment as a serious illness diagnosis.

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