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Life Expectancy for Community-Dwelling Persons with Dementia and Severe Disability

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Abstract

Background: Understanding life expectancy can help persons with dementia, their care partners, and policymakers plan for what lies ahead. We sought to determine life expectancy and predictors of mortality for community-dwelling persons with dementia and severe disability.

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Supplementary Materials include a figure detailing how participants entered our study sample (supplementary figure S1) and a description of our novel bedbound variable (supplementary figure S2).

Methods: Using the National Health and Aging Trends Study (NHATS) linked to Medicare claims, we identified community-dwelling respondents age 65+ who entered NHATS in 2011 with dementia and severe disability (defined as 3 impairments in activities of daily living), or who subsequently met criteria for dementia and then severe disability. We estimated time to death based on the timing of meeting severe disability criteria. We conducted parametric survival analyses using a Gompertz distribution to calculate risk of death and predicted median time to death. Predictors included demographic, functional, clinical characteristics, and behavioral symptoms (assessed among NHATS respondents with proxy interviews).

Results: Among 842 community-dwelling persons with dementia and severe disability, 80.5% died during the study period. After adjusting for age and gender, overall predicted median time to death was 1.7 years (25th percentile 0.6, 75th percentile 3.8 years). Six notable characteristics were associated with shorter life expectancy: 1) older age (90+), with a predicted median time to death of 1.0 year (0.4, 2.1); 2) being bedbound, 1.1 years (0.4, 2.3); 3) being homebound, 1.2 years (0.5, 2.6); 4) having comorbid cancer, 1.2 years (0.5, 2.6); 5) unintended weight loss, 1.4 years (0.5, 3.1); and 6) comorbid depression, 1.5 years (0.6, 3.3).

Conclusions: Community-dwelling persons with dementia and severe disability lived a median of 1.7 years. Clinicians can use the study findings to provide anticipatory guidance to patients and care partners, and policymakers to inform design of longitudinal supportive services.

Keywords

dementia; life expectancy; mortality; prognosis; community

INTRODUCTION:

An understanding of prognosis can help persons with dementia, their care partners, and clinicians anticipate and plan for future social, financial, functional, and clinical needs. Prior work around life expectancy and needs of persons with dementia have focused on either overall life expectancy at the time of diagnosis or on end-of-life estimates in nursing home settings. Estimates of life expectancy from onset of dementia symptoms range widely, from less than a year to more than 16 years, limiting their clinical utility.[1–3] More specific prognostic estimates in dementia have focused on facility settings[4–6] or on 6-month prognosis to determine hospice eligibility.[7,8] No studies have examined life expectancy in community-dwelling persons with dementia, despite the fact that the majority of care partners and persons with dementia want to remain at home and desire guidance on prognosis to aid planning.[10,11,12] Policymakers also support home- and community-based services, which have represented the majority of Medicaid spending on long-term supports and services since 2016.[13] As functional impairment progresses, difficult decisions often surface about additional personal care support or changes in care settings. A person with dementia and severe disability requires intensive care supports, such as assistance with bathing, dressing, and toileting. Having a more detailed understanding of the life expectancy for community-dwelling persons with dementia and severe disability could be helpful for planning and guidance.

We longitudinally followed community-dwelling persons with dementia and severe disability to identify 1) the overall life expectancy; and (2) which demographic, functional, clinical, and behavioral characteristics predicted shorter or longer life expectancy. In accordance with best practices for predictive models[14], we chose to exclude social characteristics, such as race/ethnicity, income, and educational attainment, because of our concern existing disparities could be widened if clinical care and health policy decisions are based on differential prognosis related to social characteristics rather than clinical and functional needs.

METHODS:

Design:

We used longitudinal data from the National Health and Aging Trends Study (NHATS), an annual nationally representative survey of Medicare beneficiaries age 65+. NHATS is sponsored by the National Institute on Aging and was conducted by the Johns Hopkins University. Response rates ranged from 71% in 2011 to 91% in subsequent interviews.[15] This study was approved by the Institutional Review Board of the University of California, San Francisco.

Participants:

Dementia was defined using the validated NHATS algorithm for “probable dementia” based on physician diagnosis, proxy-rated score for the Ascertain Dementia 8 screen, or impairment in memory, orientation, or executive function in cognitive exams.[16] We defined severe disability[17] as needing help with 3+ of 6 activities of daily living (ADL): eating, dressing, bathing, toileting, walking around inside, or getting out of bed. We included participants who: (1) entered NHATS in 2011 with dementia and severe disability; (2) entered NHATS in 2011 with dementia and subsequently met criteria for severe disability in 2012–2019; or (3) entered NHATS in 2011 and subsequently met criteria for dementia and for severe disability (see Supplemental Figure S1: Derivation of Study Sample). We excluded people who met criteria for severe disability before meeting dementia criteria or who were not living in the community in the round where they met criteria for severe disability.

Measurements:

To determine the date of death, we used the Medicare Master Beneficiary Summary File (2012–2017) and NHATS (2012–2019).[18] For participants who did not die, we used either the date of the last NHATS interview, or if unavailable, the last date of available CMS data, as the date of last follow-up.

We examined characteristics in the first year that the community-dwelling persons with dementia met criteria for severe disability. Demographic characteristics included age, and gender. Functional characteristics included falls, mobility device use, homebound status[19], and bedbound status (see Supplement Figure S2: Definition of Bedbound Variable). Clinical characteristics included self-reported conditions other than dementia (stroke, heart disease, lung disease, cancer, and diabetes), self-rated health, hospital stay, and symptoms.

Behavioral characteristics (hallucinations, getting lost, wandering, and not being able to be left alone) were collected only for sample persons with proxy respondents. Cognitive characteristics included memory, orientation, and executive function.

Analyses:

We examined relationships with mortality using bivariate analyses and Kaplan-Meier curves. For descriptive statistics, we used chi-square tests for categorical variables or t-tests/Wilcoxon tests for continuous measures. We conducted unadjusted and adjusted parametric survival analyses using a Gompertz proportional hazard model to calculate risk of death, predicted median time to death, and 25th and 75th percentiles. Gompertz distributions in survival regression better fit mortality data in large nationally-representative surveys than Cox proportional hazard models.[20] Adjusted modules included age and gender as characteristics previously shown to predict time to death; we did not adjust for other characteristics that might lie on the causal pathway between death and functional, clinical, or behavioral characteristics.

Analyses were conducted using SAS version 9.4 (SAS Institute, Inc., Cary, NC) and Stata version 16 (Stata Corp., College Station, TX). All analyses were weighted to adjust for unequal probability of subject selection and to account for the complex survey design variables.

RESULTS:

Among 842 community-dwelling persons with dementia and severe disability, mean age at cohort entry was 83.5±7.7 years and 57% were women (Table 1). The majority used mobility devices (81%), had chronic conditions other than dementia (77%), were bothered by pain (69%), had 1+ falls in the last year (65%), and had a hospital stay in the prior year (53%). Meaningful proportions were homebound (45%) or bedbound (10%), had fair to poor health (64%), had unintentional weight loss (40%), breathing problems (34%), had positive depression (46%) and anxiety (36%) screens. Among those with proxy respondents (n=582), common behavioral characteristics included not being able to be left alone for an hour (56%), hallucinations (33%), and getting lost in a familiar environment (28%).

Of the overall cohort, 81% (n=713) died by 2019. After adjusting for age and gender, the overall predicted median time to death for community-dwelling persons with dementia and severe disability was 1.7 years (25th percentile 0.6, 75th percentile 3.8 years, Figure 1). Below we highlight demographic, functional, clinical, and behavioral characteristics with significant differences in adjusted hazard ratios [aHR] (Table 2) and predicted median time to death (Figure 1).

Among demographic characteristics, persons with dementia and severe disability in their 90s or older had the shortest median predicted time to death, at 1.0 (25th percentile 0.4, 75th percentile 2.1) years, whereas people in their 60s and 70s had the longest median life expectancy at a median of 2.6 (1.0, 6.7) years (adjusted for gender only, aHR 2.45 [95% confidence interval (CI) 1.85–3.45]; p<0.001). Male participants had a shorter predicted median time to death at 1.4 (0.5, 3.0) years compared to female participants (median 1.9 [0.7–4.5] years, aHR 1.36 [CI 1.13–1.64]; p=0.001) (Table 2, Figure 1).

Among functional characteristics, persons with dementia and severe disability who were completely homebound had predicted median time to death of 1.2 (0.5, 2.6) years, significantly shorter than non- or semi-homebound, who had one of the longest median life expectancies at 2.2 (0.8, 5.1) years (aHR 1.74 [CI 1.40–2.16]; p<0.001). Bedbound participants had shorter predicted time to death at 1.1 [0.4, 2.3] years compared to non- or semi-bedbound (median 1.7 [0.7, 4.0] years; aHR 1.59 [CI 1.13–2.24]; p=0.009).

Among clinical characteristics, community-dwelling persons with dementia and severe disability and comorbid cancer had a predicted median time to death of 1.2 (0.5, 2.6) years, shorter than the median of 1.8 (0.7, 4.1) years of those with no cancer (aHR 1.45 [CI 1.07–1.95]; p=0.017). Participants with unintentional weight loss had a shorter median predicted time to death of 1.4 (0.5, 3.1) years compared to those with no or intentional weight loss (median 1.8 [0.7, 4.3] years, aHR 1.29 (CI 1.03–1.62); p=0.026). Those with comorbid depression had a shorter predicted median time to death of 1.5 (0.6, 3.3) years compared to those without (median 1.8 [0.7, 4.2] years, aHR 1.23 [CI 1.01–1.48]; p=0.036).

Among the subset of NHATS participants with proxy respondents (n=582) we observed differences by behavioral characteristics. Predicted median time to death was longer among participants who hallucinated (n=185) at 1.5 (0.6, 3.7) years (versus no hallucinations, median of 1.0 [0.4, 2.4] years, aHR 0.71 [0.59–0.86], p=0.001) and among those who got lost in a familiar environment (n=166) at 1.7 (0.6, 4.1) years (versus not getting lost, median 1.0 [0.4, 2.3] years; aHR 0.65 [0.52–0.81], p<0.001). Those who could not be left alone for an hour (n=329) had a shorter predicted median life expectancy of 0.9 (0.4, 2.0) years (versus can be left alone, median 1.6 (0.6, 3.9); aHR 1.68 [1.28–2.2], p<0.001).

DISCUSSION:

Our study indicates most community-dwelling persons with dementia and severe disability have a median life expectancy of 1.7 years, with 25% expected to die within 7 months and 75% within 3.8 years. We identified six notable markers of shorter predicted median life expectancy for busy clinicians: 1) being age 90+, 1.0 year; 2) being bedbound, 1.1 years; 3) being homebound, 1.2 years; 4) having comorbid cancer, 1.2 years; 5) having unintended weight loss, 1.4. years; and 6) having comorbid depression, 1.5 years. We identified two notable markers of longer life expectancy: being age 65–79, 2.6 years, and being non- or semi-homebound, 2.2 years. Behavioral characteristics were associated with both longer (hallucinations and getting lost in a familiar environment) and shorter (cannot be left alone for an hour) life expectancies. Longer life expectancies with hallucinations and getting lost ring true clinically: a person who can articulate that they are having hallucinations likely has a longer life expectancy than a similar person who cannot articulate their experiences; similarly, persons who cannot walk cannot get lost.

This study adds insight into predictors of life expectancy among community-dwelling persons with dementia and severe disability. While this work does not replace the specificity of a prognostic index, sometimes clinical risk factors are applied more broadly because they are easier for busy clinicians to remember. Based on our prior work, our findings may be relevant to a large population: our prior cross-sectional study showed that between 2012–2016, 2.2 million older adults living at home newly developed a combination of dementia and moderate disability.[21] Previous work focused on survival from symptom onset or diagnosis[22–25] or predictors of mortality for persons with dementia in facility settings such as functional impairment, bedboundness, and weight loss[8]. In outpatients, predictors of mortality include severity of disease, wandering and falling, behavioral symptoms, and major comorbid conditions[1,7].

The information provided in this study can help clinicians provide the anticipatory and prognostic guidance desired by persons with dementia and care partners[10] about what might lie ahead and time frame to consider additional care provision. Current estimates are that older adults survive 4–8 years after a diagnosis of Alzheimer’s dementia, but this can be 20 years.[13] With a 2–3 year life expectancy, serious illness conversations may include re-assessing finances, reducing polypharmacy, avoiding high-risk procedures.[26] Our prior work showed that community-dwelling persons with dementia have a lower prevalence of discussion of end-of-life preferences or completion of advanced directives compared to those without dementia.[27]

Policymakers can use these findings to inform the design of longitudinal supportive services to meet the needs of community-dwelling persons with dementia and severe disability, who may need 1 to 4 years of additional care and assistance with activities of daily living throughout the day. Though over half of nursing facility residents are estimated to have dementia,[28] the COVID pandemic has exacerbated a trend toward home-based care; persons with dementia and care partners may not want, be able to access, or be able to afford facility-based care. As such, persons with dementia and care partners need systematic supports in the home. An estimated 44% of persons with dementia use home-based clinical care each year.[29] Yet Medicaid-reimbursed services may only be available to very low-income populations, often for a maximum of 2–3 hours a day,[13] while Medicare does not pay for most long-term supports and services. Given the substantial costs, financial supports for paid caregiving at home are needed.[30]

Limitations:

Our definition of dementia and severe disability is a population measure. It does not reflect neuropsychological testing used to establish dementia severity nor does it distinguish between types of dementia syndromes.

Conclusions:

This population-level characterization of predictors of mortality for community-dwelling persons with dementia and severe disability can inform anticipatory guidance for patients and care partners and refinement of care models and policies to serve their needs. Structural supports in the community are needed to support 1–4 years of functional and clinical needs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Funding Sources and Previous Presentations:

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Key points

- Median life expectancy of community-dwelling persons living with dementia and severe disability is 1.7 years; one quarter died within 7 months.
- Life expectancy was shorter for those age 90+, bedbound, homebound, with comorbid cancer, with unintended weight loss, and with comorbid depression.

Why does this matter?

Our results have important implications for estimates of life expectancy that aid planning, guidance, and refinement of care models for community-dwelling persons living with dementia and severe disability.

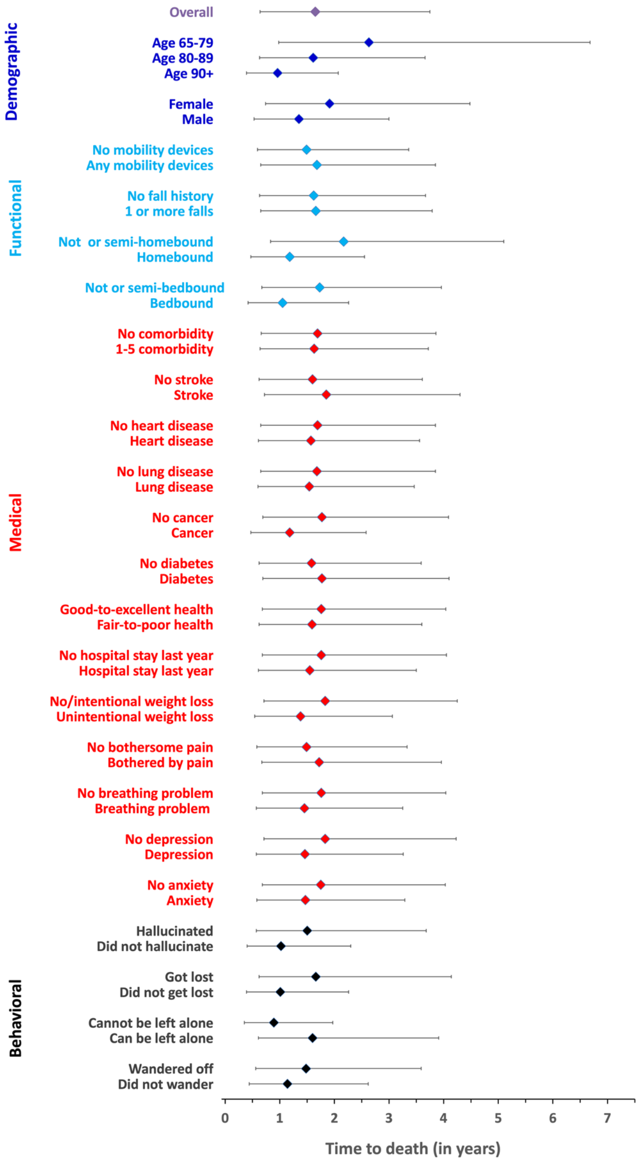

Figure 1: Predicted Median Time to Death Among Community-Dwelling Persons with Dementia and Severe Disability in the National Health Aging and Trends Study, 2011–2019.

Predicted median time to death are the predicted probabilities calculated using the post-estimation margins command following calculating adjusted Gompertz hazard ratios (where survival time is a function of the predictor variable adjusted for age and gender). In the case of age and gender, each predictor is adjusted for the other variable. The reference group from the adjusted hazard ratios is bolded is the first specified subgroup for each independent variable. Demographic characteristics are labeled in dark blue, functional characteristics in light blue, clinical characteristics in red, and behavioral characteristics in black.

Table 1:

Characteristics of Community-dwelling Persons with Dementia and Severe Disability in the National Health Aging and Trends Study 2011–2019, N=842

Characteristics	N	Weighted %
Demographic characteristics		
Age 65–79	175	29.7
Age 80–89	397	47.4
Age 90+	270	22.9
Male	328	42.6
Female	514	57.4
Functional characteristics		
No use of mobility devices	143	19.0
Used any mobility devices	699	81.0
No falls	314	35.4
≥1 falls	528	64.6
Not homebound or semi-homebound[1]	452	55.2
Homebound[1]	390	44.8
Not bedbound or semi-bedbound[2]	759	90.0
Bedbound[2]	83	10.0
Clinical characteristics		
Specific chronic condition		
Stroke	173	20.0
Heart disease	283	34.4
Lung disease	203	26.3
Cancer	140	19.0
Diabetes	262	33.0
1–5 chronic conditions other than dementia[3]	625	77.3
Excellent to good health	322	35.9
Fair or poor health	520	64.1
Hospital stay in last 12 months	435	53.3
No or intentional weight loss	527	60.4
Unintentional weight loss	315	39.6
Bothered by pain	579	69.3
Breathing problems	273	34.1
Depression (PHQ2 score, 3–6)[4]	357	45.7
Anxiety (GAD2 score 3–6)[4]	284	36.2
Behavioral characteristics[5] (n=582)		
Hallucinated	185	32.8
Got lost in familiar environment	166	28.0
Cannot be left alone an hour	329	56.4

Characteristics	N	Weighted %
Wandering & not returning by self	44	6.96
Domains of cognitive impairment [6]	353	41.7
Impairment in executive function (clock draw score)	225	25.4
In memory (immediate & delayed word recall)	355	41.7
In orientation (date, month, year, day, president, vice president)	347	40.4

[1] Limitations to home uses information in NHATS on ability and frequency of leaving that setting, based by Ornstein et al. definition.

[2] Limitations to bed uses NHATS questions on ability and frequency of leaving the bed, need help, never do by self, having difficulties, and needing devices or people to leave the bed.

[3] Includes report of doctor-identified stroke, heart disease, lung disease, cancer, diabetes.

[4] Assessments of depression (PHQ-2) and anxiety (GAD-2) experienced in the last 2 weeks. PHQ2 is the 2-item Patient Health Questionnaire (score range, 0–6); GAD-2 is the Generalized Anxiety Disorder screening tool (score range, 0–6), dichotomized at 3

[5] Behavioral symptoms are assessed only among NHATS participants whose proxies are answering on their behalf, 582 of the overall sample of 842.

[6] Cognitive assessments were conducted with 42% of the study population. Impairment in a domain is defined as having a score at or below 1.5 standard deviations from the mean. For example, 25% of the self-reporting sample had impaired executive function. People who have impairments in at least 2 domains meet criteria for having probable dementia. More information can be found on page 3 of the NHATS Technical Paper #5 on classification of persons by dementia status.

Table 2:

Risk of Death based on Gompertz Hazard Models Among Community-dwelling Persons with Dementia and Severe Disability in the National Health Aging and Trends Study, 2011–2019

Characteristics	Unadjusted[1] Hazard Ratio (95% CI)	Adjusted[1,2] Hazard Ratio (95% CI)
Demographic characteristics		
Age 80–89 (vs. 65–79)	1.42 (1.05–1.93)	1.53 (1.13–2.07)
Age 90+ (vs. 65–79)	2.19 (1.66–2.91)	2.45 (1.85–3.24)
Male (vs. female)	1.16 (0.95–1.42)	1.36 (1.13–1.64)
Functional characteristics		
Use of any mobility devices (vs. none)	1.00 (0.77–1.31)	0.90 (0.71–1.13)
≥1 falls (vs. 0 in last 12 months)	1.02 (0.84–1.23)	0.98 (0.82–1.17)
Completely homebound (vs. not or semi-homebound)[3]	1.79 (1.43–2.25)	1.74 (1.40–2.16)
Completely bedbound (vs. not or semi-bedbound)[4]	1.55 (1.09–2.22)	1.59 (1.13–2.24)
Clinical characteristics		
Specific chronic condition		
Stroke (vs. none)	0.83 (0.65–1.06)	0.88 (0.69–1.11)
Heart disease (vs. none)	1.17 (0.94–1.45)	1.06 (0.87–1.30)
Lung disease (vs. none)	1.01 (0.80–1.29)	1.09 (0.86–1.37)
Cancer (vs. none)	1.39 (1.03–1.89)	1.45 (1.07–1.95)
Diabetes (vs. none)	0.80 (0.64–1.00)	0.90 (0.73–1.12)
1–5 non-dementia conditions (vs. none)[5]	0.90 (0.72–1.12)	1.03 (0.83–1.27)
Fair or Poor Health (vs. Good to Excellent)	0.96 (0.79–1.16)	1.09 (0.90–1.33)
Hospital stay in last 12 months (vs. none)	1.14 (0.92–1.43)	1.12 (0.91–1.37)
Unintentional weight loss (vs. no or intentional weight loss)	1.32 (1.04–1.68)	1.29 (1.03–1.62)
Bothered by pain (vs. no)	0.83 (0.66–1.04)	0.87 (0.70–1.10)
Breathing problems (vs. no)	1.16 (0.92–1.47)	1.19 (0.94–1.50)
Depression (PHQ2, 3–6 vs. PHQ2, 0–2)[6]	1.18 (0.95–1.45)	1.23 (1.01–1.48)
Anxiety (GAD2, 3–6 vs. GAD2, 0–2)[6]	1.06 (0.83–1.36)	1.17 (0.93–1.47)
Behavioral symptoms[7] (n=582)		
Hallucinated (vs. not)	0.67 (0.54–0.83)	0.71 (0.59–0.86)
Got lost in familiar environment (vs. not)	0.62 (0.49–0.78)	0.65 (0.52–0.81)
Cannot be left alone an hour (vs. can)	1.63 (1.22–2.18)	1.68 (1.28–2.20)
Wandering & not returning by self (vs. not)	0.72 (0.52–0.99)	0.80 (0.58–1.10)

[1] Data presented as Hazard ratio, 95% confidence interval.

[2] Models adjusted for age and gender; age is adjusted only for gender and gender for age only.

[3] Limitations to home uses information in NHATS on ability and frequency of leaving that setting, based by Ornstein et al. definition.

[4] Limitations to bed uses NHATS questions on ability and frequency of leaving the bed, needing devices or people to leave the bed, and being unable to leave bed because of no one being able to help.

[5] Includes report of doctor-identified heart disease, diabetes, lung disease, stroke, cancer.

[6] Assessments of depression (PHQ-2) and anxiety (GAD-2) experienced in the last 2 weeks. PHQ2 is the 2-item Patient Health Questionnaire (score range, 0–6); GAD-2 is the Generalized Anxiety Disorder screening tool (score range, 0–6), dichotomized at 3).

[7] Behavioral symptoms are assessed only among NHATS participants whose proxies are answering on their behalf, 582 of the overall sample of 842.