Published in final edited form as:

Am J Med. 2019 February ; 132(2): 234–239. doi:10.1016/j.amjmed.2018.10.029.

DAYS SPENT AT HOME IN THE LAST SIX MONTHS OF LIFE AMONG COMMUNITY-LIVING OLDER PERSONS

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Abstract

Background: Days spent at home has recently been identified as an important patient-centered outcome; yet, relatively little is known about time spent at home at the end of life among community-living older persons.

Methods: The analytic sample included 457 decedents from an ongoing cohort study of 754 community-living persons, aged ≥70 years. Days spent at home were calculated as 180 days minus the number of days in a hospital, nursing home or hospice facility. The condition leading to death was determined from death certificates and comprehensive assessments.

Results: The median number of days at home was 159 (interquartile range, 125–174). 138 (30.2%) decedents were at home during the entire 6-month period, while 163 (35.7%) were at home for fewer than 150 days. Days at home did not differ significantly by age ($P=.922$), sex ($P=.238$), or race/ethnicity ($P=.199$), but did differ according to the condition leading to death ($P=.001$), with the lowest value observed for organ failure (150 [106.5–168.5]), highest values for sudden death (177 [172–179]) and cancer (167 [140–174]), and intermediate values for advanced dementia (164 [118–174]), frailty (160.5 [130–174]), and other conditions (153 [118–175]).

Conclusions: Among community-living older persons, days spent at home in the last six months of life do not differ by age, sex, or race/ethnicity, but are significantly lower for persons dying from organ failure. Additional efforts may be warranted to optimize time spent at home at the end of life, especially among older persons dying from organ failure.

At the end of life, most older persons prioritize spending days at home rather than at health care facilities.¹ This preference is highly consistent across regions of the country and socioeconomic status. Days spent at home has recently been identified as an important patient-centered goal and outcome.² New models of care, such as Hospital at Home, are being developed and evaluated,³ with the goal of reducing time spent in hospitals and other

Author Contributions:

Dr. Gill had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. The specific contributions are enumerated in the authorship, financial disclosure, and copyright transfer form.

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health care facilities, thereby allowing older persons to spend more time with loved ones in a familiar home environment.

Despite increasing recognition of its importance, relatively little is known about time spent at home at the end of life among community-living older persons. One of the few prior studies included nursing home residents and excluded persons who had managed Medicare.² In the current study, we set out to determine whether and how days spent at home in the last six months of life differ according to key demographic characteristics and condition leading to death. We postulated that older persons dying from conditions such as organ failure, which often have a fluctuating clinical course, would spend the most time in health care facilities and, hence, the least time at home in the last 6 months of life. To accomplish our objective, we used data from a well-characterized community-based cohort of older persons that includes information on health care utilization from Medicare claims, monthly telephone interviews, and medical records for more than 18 years with little attrition for reasons other than death.

METHODS

Study Population

Participants were drawn from an ongoing longitudinal study of 754 community-living persons 70 years or older, who were initially nondisabled in four essential activities of daily living (ADLs)—bathing, dressing, walking, and transferring.^{4,5} Potential participants were members of a large health plan and were excluded for significant cognitive impairment with no available proxy, life expectancy less than 12 months, plans to move out of the area, or inability to speak English. Only 4.6% of persons contacted refused screening, and 75.2% of those eligible agreed to participate and were enrolled from March 1998 to October 1999.

Data Collection

Comprehensive assessments were completed at baseline and subsequently at 18-month intervals for 216 months, while telephone interviews were completed monthly through December 2016. For participants who had significant cognitive impairment or were otherwise unavailable, a proxy was interviewed using a rigorous protocol, with demonstrated reliability and validity.⁶ Deaths were ascertained from local obituaries and/or an informant. Cause of death was coded by a certified nosologist based solely on information from the death certificate.⁷

Health Care Utilization—During the monthly interviews, information was obtained on hospitalizations and nursing home admissions. Participants were asked whether they had stayed at least overnight in a hospital since the last interview, i.e. during the past month. Based on an independent review of hospital records, the accuracy of these reports was high, with a sensitivity of 93.3% (95% CI 90.5%, 96.1%) and specificity of 99.3% (95% CI 99.0%, 99.6%).⁸ Dates of hospital admission and discharge were obtained from review of medical records.⁵ Participants were also asked whether they had been admitted to a nursing home during the past month; if yes, the interviewer noted whether the participant was currently in a nursing home. The accuracy of these reports, based on an independent review

of medical records, was high, as denoted by a sensitivity of 96.3% (95% CI 89.2, 100) and a specificity of 100% (95% CI 88.1, 100).⁸

As described in detail elsewhere,⁵ participant-level data on health care utilization was also obtained through linkages with Medicare claims and nursing home Minimum Data Set (MDS), using procedures adapted from prior studies.^{9,10} The Medicare claims are divided into files based on billing form and location of care, including hospital (acute care and rehabilitation), nursing home, and hospice facility.¹¹ For periods when participants had managed Medicare, utilization was ascertained using Medicare Provider and Analysis Review (MedPAR) files. Claims for hospice care and MDS were available for all participants regardless of plan type, i.e., fee for service or managed care.

Days Spent at Home—Days spent at home, also referred to simply as days at home, was calculated as 180 days minus the number of days in a health care facility, including hospital, nursing home, and hospice.² The primary sources for these days not at home were the Medicare claims and MDS. To enhance generalizability and minimize incomplete data, we also used information from the monthly interviews and review of medical records, especially for periods when participants had managed Medicare (mean penetrance, about 21 per 100 person-months).⁵

Classification of Condition Leading to Death—As described in an earlier report,⁷ information from death certificates and the comprehensive assessments was used to classify the condition leading to death, according to the standardized protocol provided in Table 1. Frailty was operationalized using a widely accepted and validated phenotypic definition,¹² based on data collected during the comprehensive assessment that was contemporaneous with, or immediately preceded, the last six months of life, and was assigned as the condition leading to death only when cancer, advanced dementia, or organ failure was not the condition leading to death.

Analytic Sample

Of the 669 decedents through December 31, 2016, 194 were living in a nursing home at the start of the last-6-months-of-life interval and 18 (2.7%) had incomplete information on days at home, including 8 who died within the first 6 months of follow-up, leaving 457 decedents in the analytic sample.

Statistical Analysis

Characteristics of the analytic sample were summarized using counts (percentages) and means (standard deviations [SD]). Frequency distributions were generated for number of days at home and number of days in a health care facility, including hospital, nursing home, and hospice, respectively, in the last six months of life. The number of days at home were compared according to age, sex, race/ethnicity, and condition leading to death using the Wilcoxon rank-sum test. To better understand statistically significant differences in days at home, a similar analysis was performed for number of days in the three types of health care facilities. All analyses were performed using SAS V9.4 (SAS Institute, Cary, North Carolina), and $P < .05$ (2-tailed) was used to denote statistical significance.

RESULTS

The characteristics of the 457 decedents are provided in Table 2. At the time of death, the mean age was 86.8 (SD, 6.0) years. The most common conditions leading to death were frailty, cancer, and organ failure. Deaths occurred most commonly in the hospital.

In the last six months of life, the median number of days at home was 159 (interquartile range [IQR], 125 – 174), while the mean number of days was 144 (SD, 40). The distribution of days at home is shown in the left upper panel of Figure 1. About 30% of decedents were at home during the entire period, while more than a third were at home for fewer than 150 days. As shown in the other three panels, days not at home were spent primarily in a hospital or nursing home, with a relatively small amount of time spent in a hospice facility.

As shown in Figure 2, days at home did not differ significantly by age, sex, or race/ethnicity, but did differ according to the condition leading to death, with the lowest value observed for organ failure, highest values for sudden death and cancer, and intermediate values for advanced dementia, frailty, and other conditions. These differences were driven largely by the higher number of days in a hospital and nursing home for organ failure and lower number of days in a nursing home for sudden death and cancer (Figure 3). Of the 100 decedents in the organ failure group, 54, 33, 11, and 2 died from congestive heart failure, chronic lung disease, chronic kidney disease, and cirrhosis, respectively. Median (IQR) days at home were comparable for the largest two subgroups: 150.5 (114 – 166) for congestive heart failure and 151 (99 – 174) for chronic lung disease, and were only modestly lower for chronic kidney disease (140 [68 – 166]).

DISCUSSION

In this prospective longitudinal study, we found that only three out of 10 community-living older persons spent the entire period in the last six months of life at home, as opposed to a health care facility, and more than a third were at home for fewer than 150 days. Days at home at the end of life did not differ significantly by key demographic characteristics, but did differ according to the condition leading to death. The lowest values were observed for persons dying from organ failure, who spent a relatively large number of days in a hospital or nursing home in the last six months of life.

These results provide new information about days at home at the end of life, an important patient-centered goal and outcome.² The differences observed between organ failure and other terminal conditions such as cancer may be due, at least in part, to uncertainty about prognosis.¹³ In addition, end-of-life care for congestive heart failure and chronic lung and kidney disease is often characterized by acute exacerbations, leading to repeated hospitalizations and subsequent nursing home admissions.¹⁴ To optimize time spent at home, promising programs such as Hospital at Home³ and PACE (Program of All-Inclusive Care of the Elderly),¹⁵ along with palliative care and earlier referral to home hospice,¹⁶ might be targeted specifically to older persons dying from organ failure.

Given the inherent shortcomings of using death certificates alone for assigning cause of death,¹⁷ especially for conditions other than cancer and organ failure, an important strength

of the current study is the use of data from the comprehensive assessments. These additional data allowed us to assign advanced dementia and frailty as the condition leading to death when the corresponding standard criteria were met in the absence of cancer and organ failure. Because sample size was relatively modest, organ failure was evaluated as a single group in the primary analyses. In a secondary analysis, days at home did not differ substantively across the three major organ failure subgroups.

A limitation of the current study is that information was not available on the use of palliative care. Also, because participants were members of a single health plan in a small geographic region, our results may not be generalizable to other settings. However, the demographic characteristics of the cohort reflected those of older persons in New Haven County, Connecticut, which are similar to the characteristics of the US population as a whole, with the exception of race/ethnicity.¹⁸ The generalizability of our results is enhanced by the high participation rate, low attrition, and inclusion of participants who had managed Medicare. In addition, changes in site of death over time mirrored those reported for a nationally representative sample of Medicare fee-for-service decedents.¹⁹ While days at home may differ across geographic regions,² this should have no bearing on the associations evaluated in the current study. Our values for days at home cannot be easily compared to earlier estimates, which included nursing home residents.²

In summary, only a minority of community-living older persons spend the entire period in the last six months of life at home, as opposed to a health care facility. Days at home in the last six months of life do not differ by age, sex, or race/ethnicity, but are significantly lower for older persons dying from organ failure. Additional efforts may be warranted to optimize time spent at home at the end of life, especially among persons dying from organ failure.

Acknowledgments:

We thank Denise Shepard, BSN, MBA, Andrea Benjamin, BSN, Barbara Foster, and Amy Shelton, MPH for assistance with data collection; Wanda Carr and Geraldine Hawthorne, BS, for assistance with data entry and management; Peter Charpentier, MPH for design and development of the study database and participant tracking system; and Joanne McGloin, MDiv, MBA for leadership and advice as the Project Director.

Funding and Support:

The work for this report was funded by grants from the National Institute on Aging (R01AG17560). The study was conducted at the Yale Claude D. Pepper Older Americans Independence Center (P30AG21342). Dr. Gill is the recipient of an Academic Leadership Award (K07AG043587) from the National Institute on Aging.

Role of the Sponsors:

The organizations funding this study had no role in the design or conduct of the study; in the collection, management, analysis, or interpretation of the data; or in the preparation, review, or approval of the manuscript.

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CLINICAL SIGNIFICANCE

- Only 30% of community-living older persons spend the entire period in the last six months of life at home.
- Days at home at the end of life do not differ by age, sex, or race/ethnicity, but are significantly lower for older persons dying from organ failure than from other conditions.
- Additional efforts may be warranted to optimize time spent at home, especially among older persons dying from organ failure.

Figure 1.

Number of Days Spent at Home and at Health Care Facilities in the Last Six Months of Life among 457 Decedents. All decedents were living in the community at the start of the last-6-months-of-life interval. Because days in an inpatient rehabilitation facility were very small, they were included in the hospital results. The median number of days at home was 159 (interquartile range, 125–174), which did not change over time: 159 (132–174) in 1998 to 2003, 159 (112–173) in 2004 to 2009, and 160 (128–176) in 2010 to 2016. The maximum number of days in a hospital, nursing home, and hospice facility were 122, 151, and 79, respectively.

Figure 2.

Number of Days Spent at Home in the Last Six Months of Life According to Age at Death, Sex, Race/Ethnicity, and Condition Leading to Death. All decedents were living in the community at the start of the last-6-months-of-life interval. For each box plot, the lower border, midline and upper border represent the 25th percentile, median, and 75th percentile values, respectively, while the plus sign represents the mean value. The lines from the boxes extend to the 5th and 95th percentiles, respectively. The more extreme values are represented by individual circles. *P*-values were derived from the Wilcoxon rank-sum test.

Figure 3.

Number of Days Spent at Health Care Facilities in the Last Six Months of Life According to Condition Leading to Death. All decedents were living in the community at the start of the last-6-months-of-life interval. Because days in an inpatient rehabilitation facility were very small, they were included in the hospital results. For each box plot, the lower border, midline and upper border represent the 25th percentile, median, and 75th percentile values, respectively, while the plus sign represents the mean value. The lines from the boxes extend to the 5th and 95th percentiles, respectively. The more extreme values are represented by individual circles. *P*-values, derived from the Wilcoxon rank-sum test, were .001 for days in hospital and < .001 for days in nursing home and hospice facility, respectively.

Table 1.

Protocol for Classifying the Condition Leading to Death *

Condition Leading to Death	Source of Data	Criteria †
Cancer	Death certificate	<i>ICD-10</i> codes C00.0-C97, D37.0-D37.9, D44.0-D48.7
Advanced dementia	Death certificate, Comprehensive assessment	<i>ICD-10</i> codes F01.0-F01.9, F03, G30.0-G30.9, R54, A81.0; score of 10 or less on Mini-Mental State Examination
Organ failure	Death certificate	Congestive heart failure (<i>ICD-10</i> codes I25.5, I42.0–I42.9, I50.0-I51.9), chronic lung disease (<i>ICD-10</i> codes J43.0-J44.9, J47, J61, J84.0-J84.9), chronic kidney disease (<i>ICD-10</i> codes N18.0-N18.9), or cirrhosis (<i>ICD-10</i> codes K74.0–74.6)
Frailty	Comprehensive assessment	Three or more of the following features: weight loss, exhaustion, low physical activity, muscle weakness, slow walking speed
Sudden death	Death certificate, Comprehensive assessment, monthly interview	Did not meet criteria for cancer, advanced dementia, organ failure, or frailty; reported no history of cancer, heart disease, chronic lung disease, diabetes, hip fracture, or stroke at any point during study; and was not living in a nursing home at time of death
Other conditions	Death certificate, Comprehensive assessment, monthly interview	Did not meet criteria for cancer, advanced dementia, organ failure, frailty or sudden death

* Because the conditions leading to death are not all mutually exclusive, we forced assignment of the decedents to unique groups by sequentially identifying each group and removing those decedents from the pool before identifying the next group, according to the following hierarchy: cancer, advanced dementia, organ failure, and frailty. The hierarchy was based on the premise that cancer is the dominant illness when it is listed as the immediate or underlying cause of death. For decedents who did not meet criteria for one of these four conditions, the condition leading to death was classified as sudden or other based on the standardized protocol.

† The death certificate criteria were based on the immediate or underlying cause of death. Data were used from the comprehensive assessment that was contemporaneous with, or immediately preceded, the last six months of life. *ICD-10: International Classification of Diseases, Tenth Revision.*

Table 2.

Characteristics of 457 Decedents*

Characteristic	n (%)
Age at death, y	
70 to 84	159 (34.8)
85 to 89	157 (34.4)
90 or older	141 (30.9)
Female	269 (58.9)
Non-Hispanic White	409 (89.5)
Condition leading to death	
Cancer	103 (22.5)
Advanced dementia	51 (11.2)
Organ failure	100 (21.9)
Frailty [†]	118 (25.8)
Sudden death	14 (3.1)
Other	71 (15.5)
Site of death [‡]	
Home	120 (26.3)
Hospital	169 (37.0)
Nursing home	76 (16.6)
Hospice facility	92 (20.1)
Year of death	
1998 to 2003	147 (32.2)
2004 to 2009	169 (37.0)
2010 to 2016	141 (30.9)

* Values may not sum to 100% because of rounding.

[†] Based on death certificates, there were 45 different underlying causes of death, with infection being the most common category (n=21).

[‡] Over time, values for home increased from 21.8% (1998 to 2003) to 36.9% (2010 to 2016), while values for hospital decreased from 42.2% (1998 to 2003) to 25.5% (2010 to 2016). Values for nursing home and hospice facility did not change substantively over time.