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TAKING TO BED AT THE END OF LIFE

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Abstract

Objectives: To evaluate the time course of “taking to bed” at the end of life and determine whether it differs according to age, sex, and condition leading to death.

Design: Prospective longitudinal study.

Setting: Greater New Haven, Connecticut.

Participants: 651 decedents from a cohort of 754 community-living persons, 70+ years.

Measurements: During the last two years of life, the occurrence of bed rest and number of days in bed, two indicators of bed rest burden, were ascertained each month. Bed rest was defined as staying in bed for at least 1/2 day due to an illness, injury or other problem.

Results: The occurrence of bed rest increased modestly from 12.4% at 24 months before death to 19.0% at five months before death, before increasing exponentially to 51.6% at one month before death. The median number of days in bed fluctuated within a narrow range of 3 to 7 from 24 months to four months before death, before increasing substantially to a high of 14 one month before death. In the last two years of life, the burden of bed rest did not differ by age, but was significantly greater in women than men. Among the conditions leading to death, the burden of bed rest was highest among persons dying from organ failure and cancer, lowest for sudden death, and intermediate for frailty, advanced dementia, and other conditions.

Conclusions: The burden of bed rest at the end of life is greater in women than men, does not differ by age, and is highest among persons dying from organ failure and cancer. The steep increases observed in the last three to five months of life suggest that taking to bed may be an indicator that death is approaching and should prompt discussions about referral to hospice among older persons with serious illness.

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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. All authors meet the criteria for authorship stated in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals.

Study concept and design: Gill

Acquisition of data: Gill, Gahbauer, Linda Leo-Summers

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Conflicts of Interest:

The authors have no conflicts of interest.

Keywords

longitudinal study; older persons; end of life; bed rest

In the setting of an illness or injury, older persons often “take to bed”. Prior epidemiologic research has demonstrated rates as high as 10 per 100 person-months in women and 7 per 100 person-months in men.¹ These episodes of bed rest are associated with decline in several important indicators of function, including activities of daily living, mobility, physical activity, and social activity.^{2,3} When older persons take to bed, they may become progressively weaker, deconditioned and socially isolated.

Based on our clinical experience, many older persons are particularly vulnerable to taking to bed at the end of life. Yet, relatively little is known about the time course of this phenomenon or whether it differs according to important patient characteristics such as age, sex, and condition leading to death. We postulated that the burden of bed rest at the end of life would be greater in the old-old than young-old, in women than men, and in persons dying from conditions such as organ failure and frailty that progressively diminish physiologic reserve. To test these hypotheses, we used data from a unique longitudinal study that includes monthly assessments of bed rest for more than 19 years in a large cohort of community-living older persons. Elucidating the epidemiology of bed rest at the end of life may help clinicians to better anticipate the care needs of their older patients and, in turn, to implement strategies that will optimize comfort at the end of life.

METHODS

Study Population

Participants were drawn from an ongoing longitudinal study of 754 community-living persons, aged 70 or older, who were initially nondisabled in four activities of daily living—bathing, dressing, walking, and transferring.^{1,4} Potential participants were members of a large health plan and were excluded for significant cognitive impairment with no available proxy, life expectancy <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. The study protocol was approved by the Yale Human Investigation Committee, and all participants provided informed consent.

Of the 680 decedents through December 2017, 29 (4.3%) had dropped out of the study before their last two years of life, leaving 651 decedents in the analytic sample.

Data Collection

Comprehensive home-based assessments were completed at baseline and subsequently at 18-month intervals for 234 months, while telephone interviews were completed monthly through December 2017, with a completion rate of 99%.⁴ For participants who had significant cognitive impairment or were otherwise unavailable, a proxy was interviewed using a rigorous protocol, with demonstrated reliability and validity.⁵ Deaths were

ascertained from local obituaries and/or an informant during a subsequent interview. Cause of death was coded by a certified nosologist based solely on information from the death certificate.⁶

During the comprehensive assessments, data were collected on demographic characteristics, cognitive status,⁷ and nine self-reported, physician-diagnosed chronic conditions: hypertension, myocardial infarction, congestive heart failure, stroke, diabetes mellitus, arthritis, hip fracture, chronic lung disease, and cancer.

Assessment of Bed Rest—Each month, participants were asked, “Since we last talked on (date of last interview), have you stayed in bed for at least half a day due to an illness, injury or other problem?” The test-retest reliability of this assessment was high, with Kappa = 0.84 for the occurrence of bed rest.² Starting in January 2001, participants who responded “Yes” to the bed rest question were also asked, “About how many days did you stay in bed at least half the day because of an illness, injury or other problem?” Possible responses included 1 to 30 days. Participants who were unable to provide a specific response were asked, “Would you say only 1 day, 2–5 days, 6–10 days, 11–15 days, or more than 15 days.” Because of the delayed start, about 12% of the months with bed rest did not include a corresponding value for number of days. The occurrence of bed rest and number of days in bed are two indicators of bed rest burden.

Classification of Conditions Leading to Death—Information from death certificates, comprehensive assessments, and monthly interviews was used to classify the condition leading to death, according to the protocol provided in Table S1.⁶

Statistical Analysis

The monthly occurrence (or prevalence) of bed rest was calculated by dividing the number of participants with bed rest in that month by the number interviewed in the same month using an intercept-only Poisson model. These prevalence values were plotted over the last two years of life with standard error bars and superimposition of a semi-parametric smooth curve generated with locally estimated scatterplot smoothing (LOESS).⁸ Number of days in bed were calculated among participants with bed rest in the same month and were plotted as medians across the last two years of life with a LOESS trajectory. Because these values were extremely stable, showing no variability in 1000 bootstrapped datasets, error bars were not included.

These analyses were repeated for subgroups defined on the basis of age, sex, and condition leading to death. For the occurrence of bed rest, subgroup results were compared over the last two years of life using unadjusted Poisson models with generalized estimating equations and autoregressive correlation structure for age and sex and Mantel-Haenszel chi-square statistic for equality of rates among the conditions leading to death. Differences in the distributions of days of bed rest for age and sex were evaluated using the non-parametric Wilcoxon statistic. The non-parametric Kruskal-Wallis statistic was used to test for equality of the medians among the six conditions leading to death.

All analyses were performed using SAS V9.4 (SAS Institute, Cary, North Carolina, with $P < .05$ (2-tailed) denoting statistical significance.

RESULTS

The characteristics of the 651 decedents are provided in Table 1. The mean (SD) age was 86.4 (5.9) years. Nearly 18% of decedents were living in a nursing home at the start of the last two-years-of-life interval. The most common conditions leading to death were frailty, advanced dementia, and organ failure.

The monthly occurrence of bed rest in the last two years of life is shown in the top panel of Figure 1. Values increased modestly from 12.4% at 24 months before death to 19.0% at five months before death, before increasing exponentially thereafter to 51.6% at one month before death. The cumulative rate of bed rest over this 2-year period was 89%. The bottom panel of Figure 1 provides the monthly values for days in bed among participants with bed rest in the same month. The median values fluctuated within a relatively narrow range of 3 to 7 from 24 months to four months before death, before increasing substantially thereafter to a high of 14 one month before death.

As shown in Figure 2 (left column) and Table S2 (top panel), the occurrence of bed rest in the last two years of life did not differ by age, but was significantly greater in women than men. For the conditions leading to death, the occurrence of bed rest was highest for organ failure and lowest for sudden death, with intermediate values for cancer, advanced dementia, frailty, and other. As shown in Figure 2 (right column) and Table S1 (bottom panel), days in bed did not differ substantively by age or sex, although the small differences observed in the figure, with greater values for women than men, were statistically significant. For the conditions leading to death, days in bed were greatest for cancer and organ failure, lowest for sudden death, and intermediate for advanced dementia, frailty, and other.

DISCUSSION

In this prospective longitudinal study of community-living older persons, we found that the burden of bed rest was relatively stable in the last two years of life until about three to five months prior to death when both the occurrence of bed rest and number of days in bed increased substantially. The burden of bed rest in the last two years of life did not differ by age, but was significantly greater in women than men. Among the conditions leading to death, the burden of bed rest was highest among persons dying from organ failure and cancer, lowest for sudden death, and intermediate for frailty, advanced dementia, and other conditions. These results provide new information that may help clinicians to better anticipate the care needs of their older patients and, in turn, to implement strategies that will optimize comfort at the end of life.

We had postulated that the burden of bed rest at the end of life would be greater in the old-old than young-old, in women than men, and in persons dying from conditions such as organ failure and frailty that progressively diminish physiologic reserve. Although our hypotheses about sex differences and organ failure were confirmed, we found no age-related differences in either the occurrence of bed rest or number of days in bed. In an earlier study, which

included all participants, the occurrence of bed rest was also significantly greater in women than men.¹ The median duration of follow-up, however, was only 15 months, and neither the number of days in bed or the effect of age was evaluated.

We found that the occurrence of bed rest was comparable in participants dying of frailty and cancer, but the number of days in bed was greater for the latter than the former. As shown in Figure 2 (right panel), the number of days in bed was highly variable for cancer from one month to the next, in contrast to dementia, organ failure, frailty, and other conditions, where the number of days in bed was relatively stable until the last three months of life when the values increased substantially. Although the source of variability for cancer is uncertain, it could be attributable to the timing and adverse consequences of treatment.

Prior research and clinical experience suggest that “taking to bed” likely diminishes quality of life. Episodes of bed rest are associated with decline in several important indicators of function, including instrumental activities of daily living, mobility, physical activity, and social activity,² and with transitions to more severe states of disability.³ Given the steep increases observed in the last three to five months of life, taking to bed may be an indicator that death is approaching in older persons with serious illness. Although palliative care should be considered early in the course of a serious illness, especially when bothersome symptoms are present, our results suggest that taking to bed should prompt discussions about referral to hospice.

Our ascertainment of bed rest had three important strengths. First, exposure was assessed monthly with a completion rate of nearly 100%; second, the reliability of these assessments was high; and third, exposure was linked to an illness, injury or other problem. In addition, the number of days in bed was ascertained for all but 12% of the months with bed rest. Other strengths of the study include the low rate of attrition for reasons other than death and use of death certificates, along with data from the comprehensive assessments and monthly interviews, to determine the condition leading to death. Because participants were members of a single health plan in a small urban area and were oversampled for slow gait speed, our results may not be generalizable to older persons in other settings. However, the demographic characteristics of our 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 or ethnic group.⁹ The generalizability of our results is also enhanced by our high participation rate, which was greater than 75%.

In summary, the burden of bed rest at the end of life is greater in women than men, does not differ by age, and is highest among persons dying from organ failure and cancer. The steep increases observed in the last three to five months of life suggest that taking to bed may be an indicator that death is approaching and should prompt discussions about referral to hospice among older persons with serious illness.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.

Bed Rest in the Last Two Years of Life. The top panel shows the monthly occurrence of bed rest, which was calculated by dividing the number of participants with bed rest in that month by the number interviewed in the same month. The bars denote 1 standard error around mean values. The bottom panel provides the monthly values for days in bed among participants with bed rest in the same month. Because the median values were extremely stable, showing no variability in 1000 bootstrapped datasets, error bars are not included.

Figure 2.

Bed Rest in the Last Two Years of Life According to Age, Sex and Condition Leading to Death. The left panel shows the monthly occurrence of bed rest, which was calculated by dividing the number of participants with bed rest in that month by the number interviewed in the same month. Bars, denoting 1 standard error around mean values, are provided for age and sex but not condition leading to death because of the large number of strata. The right panel provides the monthly values for days in bed among participants with bed rest in the same month. Error bars are not included for age and sex because the median values were extremely stable, showing no variability in 1000 bootstrapped datasets, or for the condition leading to death because of the large number of strata.

Table 1.**Characteristics of Decedents¹**

Characteristic	N=651
Age in years, n (%)	
70 to 84	289 (44.4)
85 or older	362 (55.6)
Female, n (%)	412 (63.3)
Non-Hispanic white, n (%)	591 (90.8)
Education in years, mean (SD)	11.9 (2.9)
Living in nursing home, n (%)	114 (17.6)
Number of chronic conditions, ² mean (SD)	2.5 (1.3)
Condition leading to death, n (%)	
Cancer	109 (16.7)
Advanced dementia	135 (20.7)
Organ failure	134 (20.6)
Frailty	182 (28.0)
Sudden death	14 (2.2)
Other	77 (11.8)

Abbreviation: SD, standard deviation.

¹ Age and nursing home residence were determined at the start of the last two-years-of-life interval, and number of chronic conditions was determined during the comprehensive assessment that preceded the last two years of life.

² Chronic conditions included hypertension, myocardial infarction, congestive heart failure, stroke, diabetes mellitus, arthritis, hip fracture, chronic lung disease, and cancer.