Terminal Trajectories of Functional Decline in the Long-Term Care Setting

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Background. Little is known about the terminal trajectories of functional decline among long-term care (LTC) residents dying with different diseases.

Methods. A retrospective cohort study was performed on 747 individuals aged 65 or older who died between January 1994 and December 2004 in a 675-bed LTC facility in Massachusetts. Three study groups were created: advanced dementia, n = 314 (42%); terminal cancer, n = 63 (8%); and organ failure (congestive heart failure and chronic obstructive pulmonary disease), n = 370 (50%). Quarterly scores of 7 activities of daily living (ADLs) during the last year of life derived from the Minimum Data Set were compared among the three groups. Each activity was rated from 0 to 4 (higher scores indicate more dependence; total range, 0–28).

Results. The mean age of all individuals at death was 91 ± 6 (standard deviation) years. Functional decline was greatest during the last 3 months of life, but this decline was most precipitous in the terminal cancer and organ failure groups compared to the advanced dementia group. The mean change in ADL scores during the last year of life differed among the three groups (p < .001), with the greatest decline in the terminal cancer group (from initial score 13 to final score 25), followed by the organ failure group (13 to 22), and finally, the advanced dementia group (24 to 27).

Conclusions. The terminal trajectories of functional decline among LTC residents vary by underlying diseases. An understanding of these trajectories may be useful to clinicians and families caring for LTC residents near the end of life.

O VER 1.6 million Americans reside in nursing homes (1). As such, the long-term care (LTC) setting is a major site of terminal care for frail older persons. Although functional decline is expected near the end of life (2–10), the terminal trajectories of functional loss among LTC residents have not been well-described.

The varying patterns of functional loss among different terminal diseases have potentially important implications for palliative care. Patients and families are more likely to choose care directed toward comfort if they perceive that the end of life is near (11). As such, the decision to transition from life-prolonging to palliative care could be facilitated by the recognition that an abrupt decline in function may herald the terminal stage of an illness. In contrast, functional status may be less informative for end-of-life decision-making in conditions that tend not to manifest appreciable changes in function as death approaches.

Earlier work has demonstrated that the patterns of functional decline among the terminally ill are influenced by underlying health conditions (2–9). Most notably, these studies have described a sharp functional decline just prior to death for persons with terminal cancer, compared to a more gradual functional loss over time for persons dying with chronic diseases (4,5). While providing important insights, this earlier work has several limitations. First, most prior studies examined community-dwelling older persons (2–5,9,10), whose terminal trajectories of functional decline conceivably differ from those of institutionalized populations. Second, these prior studies did not specifically compare the functional decline in persons with advanced dementia to that in persons with other illnesses (7,8). Finally, although prior work has described the terminal trajectories of global functional status, few studies have examined the patterns of loss for specific activities of daily living (ADLs) (8), which may be particularly informative for LTC populations.

To better understand the patterns of functional decline in LTC populations, this report examines the final year of life of residents dying with three different conditions: advanced dementia, terminal cancer, and organ failure. The objectives of this study were to describe and compare the trajectories of functional decline in these three cohorts, and to examine the specific ADL loss as they approach the end of life.

METHODS

Participants

This study was approved by the Institutional Review Board at Hebrew SeniorLife (HSL). Eligible individuals included all residents of HSL aged 65 years or older who died between January 1, 1994 and December 31, 2004. HSL is a 675-bed academic LTC in Boston, Massachusetts, with an almost all white, Jewish population and closed medical
staff. Decedents were identified by the HSL medical record department. To describe functional decline during the last year of life, only decedents whose length of stay was ≥ 1 year were included.

Residents who died with advanced dementia, terminal cancer, or organ failure were identified using data from computerized Minimum Data Set (MDS) assessments completed 1 year prior to death. The MDS is a federally mandated, standardized comprehensive assessment instrument used in all licensed U.S. LTC facilities (12–15). At HSL, physicians complete the diagnoses section of the MDS, and trained nurses complete the remainder of the assessment. An MDS assessment is completed at the time of admission, quarterly thereafter, and whenever there is an acute change in status. Residents who did not have an MDS conducted during their last month of life had an assessment completed within 2 weeks of death.

Advanced dementia was defined as having a dementia diagnosis and a Cognitive Performance Scale (CPS) score of 5 or 6. The CPS is a validated instrument that uses five MDS items to group individuals into seven hierarchical cognitive performance categories ranging from 0 (intact) to 6 (very severe impairment) (13). A CPS score of 5 corresponds to a mean Mini-Mental State Examination score of 5.1 ± 5.3 (standard deviation [SD]) (13,16). Terminal cancer was defined as having a cancer diagnosis (intra-class coefficient [IC] = .81) (17) [MDS does not specify the type of cancer (18)] and a perceived life expectancy < 6 months (a specific MDS variable) (IC = .58).

Based on the literature (4), residents were included in the organ failure group if they had congestive heart failure (CHF) (IC = .83) or chronic obstructive pulmonary disease (COPD) (IC = .75) (17).

Frail older persons commonly have many comorbid conditions. To create three mutually exclusive study groups, we chose the hierarchy of advanced dementia equal to terminal cancer, both of which were greater than organ failure. Thus, advanced dementia and terminal cancer groups were created first, and persons with both diagnoses were excluded (n = 13). However, residents in these two groups were permitted to have CHF or COPD. The organ failure group was created last. Individuals in this group could not have advanced dementia or terminal cancer, but were permitted to have mild to moderate dementia (i.e., CPS score < 5), and nonterminal cancer (i.e., life expectancy > 6 months).

**Functional Status and Other Variables**

Functional disability was measured using the ADL Scale based on data obtained from quarterly MDS assessments during the last year of life (14). The scale measures the residents’ ability to perform seven ADLs: bed mobility, transferring, dressing, eating, locomotion, toileting, and personal hygiene (average IC = .91) (17). Performance of each ADL is rated as follows: 0 = independence, 1 = needs supervision, 2 = needs limited assistance, 3 = needs extensive assistance, and 4 = total dependence. The total ADL score ranges from 0 (total independence) to 28 (total dependence). The final year of life was divided into four 3-month time windows: 0–3 months before death, 3–6 months before death, 6–9 months before death, and 9–12 months before death. Decedents who did not have an MDS assessment in each of the four time windows were excluded from the analyses. If more than one MDS assessment was done for a resident within one time window, the ADL score was obtained from the assessment completed closest to death. For example, if more than one assessment was done between 3 and 6 months prior to death, the ADL score determined from the assessment completed closer to 3 months before death was used. Finally, age at death and gender were determined for all persons.

**Statistical Analyses**

Statistical analyses were conducted using SAS, version 9.1 for Windows (SAS Institute, Inc., Cary, NC). Descriptive statistics were computed for age at death, gender, total ADL scores, and the functional performance on each ADL Scale item. Repeated-measures analysis of covariance was performed using the PROC MIXED (19) procedure to examine whether the total ADL scores differed by time (time effect), by disease (group effect), or by time and disease (interaction effect), after adjusting for age at death and gender. Similar analyses were conducted for the
performance scores on each individual ADL. The PROC MIXED procedure permits missing observations and accounts for the correlation among repeated measures within individuals. Adjusted mean scores of the total ADL Scale and each of the seven individual ADL domains were reported separately for each disease group for each time window. Subgroup analyses showed that the functional trajectories were similar for the persons with CHF and COPD in the organ failure group. We felt that it was reasonable to combine them.

RESULTS

Characteristics

Among 1694 residents aged 65 or older who died at HSL during the study period, 372 (22.0%) were excluded because their length of stay was < 1 year, and an additional 225 (13.3%) residents were excluded because they did not have MDS assessments completed during each time window (Table 1). Another 350 persons did not fulfill criteria for one of the three disease groups. The remaining 747 residents were classified into: advanced dementia, \( n = 314 \) (42.0%); terminal cancer, \( n = 63 \) (8.5%); or organ failure, \( n = 370 \) (49.5%) (Table 2). The individuals included in the final study sample were significantly older (mean age, 91.1 ± 6.1 SD vs 89.7 ± 6.8 SD years, \( p < .001 \)) and more likely to be female (74.0% vs 69.5%, \( p = .04 \)) compared to the decedents excluded from analysis (\( n = 947 \)) (data not shown). The distribution of disease diagnoses and the total ADL scores at death among those persons excluded from final analysis are reported in Table 1.

The mean ages and gender distributions of the 747 persons included in the analysis did not differ significantly among the three study groups (\( p = .11 \) and .05, respectively) (Table 2). The distribution of disease diagnoses and mean total ADL scores at study entry among the individuals are summarized in Table 2.

Overall Functional Status During the Last Year of Life

Figure 1 presents the age- and gender-adjusted mean total ADL scores during the last year of life. Mean ADL scores increased (i.e., functional status worsened) significantly (\( p < .001 \)) in all three groups from 9–12 months to 0–3 months before death as follows: advanced dementia, 24.2 to 26.6; terminal cancer, 12.7 to 25.0; and organ failure, 13.1 to 21.5. The persons with advanced dementia were more functionally disabled than those in the other two groups throughout the last year of life, although as a group they were slightly below the maximum ADL score 9–12 months prior to death. Mean total ADL score increments for each 3-month interval were 0.8 (95% confidence interval [CI], 0.7–0.9) for advanced dementia, 3.9 (95% CI, 3.2–4.6) for terminal cancer, and 2.7 (95% CI, 2.5–2.9) for organ failure (\( p < .001 \) for trends in all groups).

During the last 3 months of life, persons with terminal cancer had an acute decline in functional status (a mean 9.1-point increase in total ADL scores) to ultimately reach total ADL scores comparable to those of persons dying with advanced dementia (25.0 vs 26.6, \( p = .08 \)). Individuals in both the terminal cancer and organ failure groups experienced steeper declines in function during the final 3 months of life compared to those in the advanced dementia group.

Performance of Individual ADL Domains During the Last Year of Life

Figure 2 presents the ability of persons in each disease group to perform six individual ADLs (eating, transferring, locomotion, toileting, dressing, and personal hygiene) during the last year of life. (ADL scores for bed mobility

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Advanced Dementia (( N = 314 ))</th>
<th>Terminal Cancer (( N = 63 ))</th>
<th>Organ Failure (( N = 370 ))</th>
<th>( p ) Value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at death, mean ± SD (y)</td>
<td>90.6 ± 6.3</td>
<td>90.6 ± 6.2</td>
<td>91.6 ± 5.9</td>
<td>.11</td>
</tr>
<tr>
<td>Female, %</td>
<td>78.3</td>
<td>66.7</td>
<td>71.6</td>
<td>.05</td>
</tr>
<tr>
<td>Total ADL score at study entry, mean ± SD</td>
<td>24.3 ± 5.5</td>
<td>12.6 ± 9.6</td>
<td>13.0 ± 8.6</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Congestive heart failure, %</td>
<td>27.4</td>
<td>49.2</td>
<td>90.3</td>
<td>NA</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease, %</td>
<td>9.9</td>
<td>14.3</td>
<td>21.6</td>
<td>NA</td>
</tr>
<tr>
<td>Mild to moderate dementia (CPS &lt; 5), %</td>
<td>NA</td>
<td>50.8</td>
<td>61.4</td>
<td>NA</td>
</tr>
<tr>
<td>Nonterminal cancer (life expectancy ≥ 6 months), %</td>
<td>14.6</td>
<td>NA</td>
<td>8.6</td>
<td>NA</td>
</tr>
</tbody>
</table>

Notes: *\( p \) value indicates global comparisons.

\( SD = \) standard deviation; ADL = Activities of Daily Living; NA = not applicable.
were very similar to transferring; therefore, only data for transferring are presented.) The mean score for each ADL Scale item declined as individuals in all three groups approached death. Persons with advanced dementia were more disabled in all ADLs compared to those with terminal cancer or organ failure up until the last 3 months of life. Persons in all study groups retained the greatest independence in eating and transferring during the last year of life. On average, individuals with terminal cancer and organ failure were completely independent or only required supervision (mean ADL scores < 2.0) with these two tasks up until the last 3 months of life, after which their performance declined precipitously. Although the persons with advanced dementia required extensive assistance for eating and transferring during the last year of life, only these two tasks did not demonstrate complete dependence until just prior to death.

DISCUSSION

This study indicates that, among LTC residents, trajectories of functional decline in the last year of life vary
significantly among different conditions. Specifically, residents with advanced dementia showed severe functional dependence throughout the last year of life with little opportunity to worsen as death approached. In contrast, residents with terminal cancer and organ failure experienced mild to moderate functional disability up until 3 months prior to death, at which point there was a sharp decline in functional status. In all groups, eating and transferring were relatively less impaired than other ADLs until the last 3 months of life.

Our study corroborates prior studies examining functional decline in terminally ill patients (4,5,8) and extends these findings to the LTC setting and to persons dying with advanced dementia. In a population-based study, Lunney and colleagues (4) described patterns of functional decline during the last year of life of primarily community-dwelling elders who died from sudden death, cancer, organ failure (CHF and chronic lung disease), and frailty (had a nursing home admission in the last year of life, but did not necessarily permanently reside in a nursing home). Although our LTC sample demonstrated greater overall disability during the year prior to death, the patterns of decline in the terminal cancer and organ failure groups in our study were similar to the comparable groups in the report by Lunney and colleagues (4). A study by Teno and colleagues (5) also reported similar dying trajectories among cancer patients as compared to patients with other chronic diseases.

Few prior studies have described patterns of functional decline specifically among LTC residents (6–8). Using MDS data from 76,016 long-stay nursing home residents in five states, McConnell and colleagues (7) demonstrated that residents with greater cognitive impairment (as measured by the CPS) had worse functional ability than more intact residents had. However, their study did not examine functional changes near the end of life or compare different diseases. Covinsky and colleagues (8) studied 937 community-dwelling, but nursing home-eligible, older persons. Their study found that persons with cognitive impairment had higher levels of functional impairment than did persons with intact cognition throughout the last 2 years of life, but the analysis did not stratify functional trajectories by severity of cognitive impairment, or compare different disease states.

Our study demonstrates that individual ADLs show different patterns of decline as death approaches in LTC residents. Most notably, the abilities to eat and transfer were relatively preserved until death was imminent, especially for individuals with terminal cancer and organ failure other than dementia. This finding supports and extends a community-based report that demonstrated that a hierarchical loss of individual ADLs as cognitive function deteriorates with eating being the last preserved function (20). Covinsky and colleagues (8) also reported that, for patients without cognitive impairment in Program of All-inclusive Care of the Elderly (PACE), the prevalence of dependency on eating increased from 20% to 40% in the last year of life, and from 60% to 75% for persons with cognitive impairment.

Our study has several limitations that deserve comment. First, functional status was only measured at four time points during the last year of life. Thus, we were unable to describe fluctuations that may have occurred between these assessments. It is not likely that more frequent measures would have demonstrated appreciable variations in functional status in the advanced dementia group, but may have possibly varied to a greater degree among persons with terminal cancer and organ failure. Second, misclassification of disease groups may occur with MDS data. However, the diagnoses section on the MDS was filled out by physicians at HSL, thus minimizing the potential of misclassification. Finally, death certificates were unavailable. Therefore, although the individuals died with the conditions captured in the three disease groups, we cannot be certain that these conditions were necessarily the ultimate cause of death.

Summary
Significant declines in physical functioning may herald impending death for LTC residents with terminal cancer or organ failure, especially when the abilities to transfer and eat independently are lost. Greater focus of palliative care may be appropriate at this time point. However, for residents with advanced dementia, functional ability is a less sensitive marker of terminal status, as severe impairment is present throughout the last year of life. An understanding of these trajectories of functional decline may be useful to clinicians and families caring for LTC residents near the end of life.

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References


