

# Dying Trajectory in the Last Year of Life: Does Cancer Trajectory Fit Other Diseases?

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## ABSTRACT

**Purpose:** To examine differences in the pattern of functional decline among persons dying of cancer and other leading noncancer causes of death.

**Design:** Mortality followback survey of next of kin listed on death certificate.

**Setting:** Probability sample of all deaths in the United States.

**Participants:** Next of kin for 3,614 decedents that represented 914,335 deaths.

**Measurements:** Days of difficulty with activities of daily living and mobility in the last year of life.

**Results:** Relative to other decedents, patients with cancer experienced an increased rate of functional impairment beginning as late as 5 months prior to death. For example, only 13.9% of patients with cancer had difficulty getting out of bed or a chair 1-year prior to death. This increased from 22.2% to 63.0% in the last five months of life. In contrast, decedents from other diseases had higher rates of functional impairment 1 year prior to death (approximately 35% had difficulty getting out of bed or chair) and they manifested a more gradual increase in the level of functional decline (approximately 50% had difficulty getting out of bed). Precipitous functional decline was associated with hospice involvement and dying at home.

**Conclusion:** Persons dying of cancer experienced sharp functional decline in the last months of life whereas other decedents' have a more gradual decline. The more precipitous functional decline was associated with hospice involvement and dying at home.

## INTRODUCTION

AMERICANS FEAR DYING in pain, surrounded by technology, and isolated from loved ones.<sup>1</sup> The hospice movement was born out of these concerns, with the goal of allowing persons to die in familiar settings with the best possible quality of life. Yet only a minority of the dying use hospice services and a cancer diagnosis is predominant among users.<sup>2</sup> The differential use of hospice by cancer patients is explained by the predictable

disease trajectory these patients experience in the last months of life.<sup>3</sup> Persons dying of cancer often lose weight and have precipitous functional decline which act as harbingers of death. The U.S. Medicare Hospice Benefit was created based largely on a cancer death trajectory. Current debate has focused on how this benefit can appropriately be extended to include persons dying of other disease with potentially, quite different dying trajectories<sup>4-7</sup> Central to this debate is whether the dying trajectories of noncancer ill-

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nesses fit the expected trajectory covered by the Medicare Hospice Benefit.

The claim that health care ought to be organized around dying trajectories is not new. In 1968, Glaser and Strauss<sup>8</sup> recommended that the observed differences in dying trajectories inform the organization of health care delivery. However, the trajectory of the dying process is not based on objective on various factors from objective physiological parameters to the kinds of treatments received<sup>9</sup> and the psychological will to live.<sup>10</sup> However, despite the universal eventuality of death, little research has been done to characterize various dying trajectories, and in particular how these trajectories differ by leading causes of death.

Using qualitative research methods, Glaser and Strauss<sup>8</sup> described the trajectories common for sudden unexpected deaths as well as the lingering trajectories, which are often experienced in chronic illnesses. They noted that there were critical junctures that signify important turning points.<sup>8</sup> Few studies have quantitatively characterized the dying trajectory.<sup>3,11,12</sup> Morris and colleagues<sup>3</sup> found that cancer patients enrolled in hospice had a precipitous functional decline in the last 1–2 months of life. However, because patients enrolled in hospice and declined further active treatment for their disease, this trajectory may not be generalizable. Two studies have found a downward trajectory in the last year of life for small, geographically defined populations. Lawton and colleagues<sup>12</sup> asked bereaved family members to recall the quality of life 12 months, 3 months, and 1 month prior to death for older adults dying in Philadelphia, Pennsylvania. Brock and colleagues<sup>13</sup> performed a similar study in one Connecticut county that examined the quality of life and function at 12 months, 1 month, and the day prior to death. Each of these studies found that function and quality of life declined over the last year of life.

To date, no study has compared dying trajectories of decedents of the leading causes of death in the United States. Although researchers have reported the proportion of individual reporting difficulty functioning in the last year of life,<sup>14,15</sup> our research effort focuses on determining national estimates of rates of functional decline, for both cancer and other leading noncancer causes of death, using data from the 1993 U.S. National Mortality Followback Survey (NMFS).

## METHODS

Since the 1960s, the National Center for Health Statistics has conducted representative studies of all deaths in the United States based on in-depth interviews with bereaved next of kin listed on death certificates. The 1993 survey represents the sixth national survey that collects information on sociodemographic information, psychological state, life-long use of alcohol and medications, lifestyle, health care resource utilization, and difficulties with functioning.<sup>15,16</sup>

## SAMPLE

A systematic 1% sample was drawn from the current mortality sample that includes death certificates from 50 states, the District of Columbia, and the independent registration area of New York City. All localities with the exception of South Dakota allowed public release of the listed next of kin. Based on these death certificates, a complex sampling scheme was created that oversampled certain demographic groups (e.g., African Americans) and certain diseases (e.g., cardiovascular deaths). Data were analyzed using the sample weights provided by National Center for Health Statistics.<sup>16</sup> This sampling scheme allows each respondents' data to be weighted to represent all those persons who died in 1993.

### *Survey methods*

A letter requesting participation in the NMFS was sent to the informant listed on the death certificate. If there was no informant listed, a letter was sent to the funeral home asking for that information. When there was no next of kin, another person familiar with the decedents' life history was contacted. The response rate was 83%.

The survey obtained data on nearly 1,000 items focused in 23 domains. Information regarding the onset of difficulty performing activities of daily living (bathing, dressing, eating, transferring the ability to rise from a chair or get out of bed, and using the toilet), and mobility (lifting 10 pounds, climbing stairs, walking one-quarter mile, and getting around the inside of the house) was obtained. For each activity that the decedent had difficulty with, the proxy respondent was asked the length of time that the person had difficulty doing that activity.

## DATA ANALYSES

Our analysis focuses on those decedents who died from cancer (defined as International Statistical Classification of Diseases, 9th Revision [ICD 9] 140 to 208) or one of the four leading noncancer causes of death. These include (1) congestive heart failure (ICD 9 394, 395, 424.0 to 424.9, 425.4, 428); (2) diabetes mellitus (ICD 250); (3) cerebral vascular accident (ICD 9 430 to 438); and (4) chronic obstructive pulmonary disease (ICD 9 490 to 493, 496).

For each cause of death, we examined the trajectory of functional decline of activities of daily living (ADL) in the last year of life. A composite score for evaluating the difficulties the decedent had with ADL was constructed by counting the number of items where the proxy reported difficulty (from 0–5, with 5 indicated difficulty in all ADL items examined). For each disease, we graphed the proportion of decedents who no longer functioned independently for every month prior to death. The rate of ADL impairments was adjusted for differences in age among the five causes of death.

To examine whether there were different patterns of decline in the five disease categories, we used a one-way analysis of variance. To examine the impact of functional decline on site of death and hospice referral, we examined the association of functional decline in the last 5 months with hospice involvement and site of death (defined as dying at home or not). This was examined using a Mantel-Hanzel test for linear trend.

## RESULTS

Table 1 presents the demographic data for persons who died of cancer and the leading noncancer causes of death, i.e., congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), cerebral vascular accident (CVA), and diabetes mellitus (DM). These 3,614 deaths represent 914,335 of the 2,215,440 deaths in the United States in 1993. Demographic differences were seen among these diseases, with cancer and DM affecting a slightly younger population. Women were more likely to die of DM, CHF, or CVA. African Americans were more likely to die of DM. A spouse was more likely to be the respondent for persons who died from cancer, while children were the respondents in 34.4% to 38.1% for the four other causes of death. Cancer

decedents were more likely to die at home. More than one in three (35.8%) died at home, while nearly two thirds of persons with CVA, COPD, and DM died in an acute care hospital. More persons with CHF and CVA were likely to die in a nursing home (31.2 and 27.4, respectively). Overall, 17.5% of all decedents used hospice care, although cancer decedents are most likely to have hospice involvement.

Figure 1 depicts the rate of functional decline during the last 12 months of life after adjustment for age of the decedent. The X axis goes from 12 months prior to death on the left to the day before death on the extreme right. One year prior to death, persons dying from cancer were less functionally impaired than were other decedents at a similar point in time. Only 20% of the persons dying from cancer had any ADL impairments one year prior to death, whereas more than 40% of noncancer causes of death were already ADL impaired. The mean number of ADL impairments 12 months prior to death in noncancer causes of death varied between 1.3 and 1.6. All five diseases exhibited a functional decline that was relatively flat until the last 5 months of life. At that time, persons dying from cancer went from a mean of 1.0 to 3.0 ADL impairments, while those dying of noncancer causes increased their mean ADL impairment from 1.6 to 2.3. For each ADL and mobility items, the number of days with difficulty functioning was statistically significant (i.e.,  $p < 0.001$ ) for cancer compared to noncancer decedents as test by one-way analysis of variance.

Figure 2 depicts the percentage of persons who were limited in mobility to the point that they could not transfer out of bed or chair for 12 months preceding death. Only 13.9% of cancer patients had difficulty getting out of bed or a chair 1 year prior to death. This increased from 22.2% to 63.0% in the last 5 months of life. People with noncancer diseases had higher rates of functional impairment 1 year prior to death (approximately 35% had difficulty getting out of bed or a chair), but they experienced a gradual increase in the levels of functional impairment than did cancer decedents (approximately 50% had difficulty getting out of bed during the final months of life).

The pattern of functional decline was associated with hospice involvement and site of death (Table 2). Among decedents with a sharp functional decline in the last 5 months of life, 29% had hospice involved in their care compared to 6.5%

TABLE 1. CHARACTERISTICS OF SAMPLED INDIVIDUALS WHO DIED FROM CANCER, CONGESTIVE HEART FAILURE (CHF), DIABETES MELLITUS (DM), CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD), OR CEREBRAL VASCULAR ACCIDENT (CVA)

Characteristics	Cancer	CHF	DM	COPD	CVA
1993 U.S. decedents	526,432	83,640	51,927	101,202	151,134
Survey sample size	1655	291	157	1059	452
Age (mean, median, 25th, 75th percentile)	70.1 62 32 76	78.1 68 31 99	70.0 65 34 81	75.0 74 67 81	79.4 81 64.5 99
Education (mean, median, 25th, 75th percentile)	12.1 12 11 13	12.5 12 12 14	12.6 12 12 14	12.2 12 11.4 14	12.2 12 11.6 13.2
Gender (% male)	52.0	44.9	35.7	53.2	44.3
Race (%)					
White	87.3	89.5	76.2	93.7	86.1
African American	11.2	10.4	17.9	5.9	10.5
Other	1.5	0.1	5.9	0.4	3.4
Marital Status (%)					
Widowed	28.2	56.5	44.6	39.0	48.8
Divorced/separated	8.4	4.4	7.4	10.4	8.0
Never married	6.0	8.5	2.2	5.4	6.0
Relationship of the respondent to the decedent (%)					
Spouse	40.1	18.9	26.8	28.8	24.1
Child	28.9	35.6	34.7	34.4	38.1
Other relative	24.9	41.5	34.2	30.0	24.5
Friend	2.4	0.3	4.2	2.7	3.9
Other relationship	3.8	3.7	0.2	4.2	9.4
Site of death (%)					
Hospital	47.0	42.3	62.4	64.3	61.5
Nursing home	14.2	31.1	14.4	17.2	27.4
Home	35.8	23.2	22.4	15.8	8.9
Other	2.4	1.7	0.6	1.0	1.5
Hospice involved (%)	19.7	4.9	2.9	7.1	3.1

hospice involvement when there were no changes in ADL impairment (Mantel-Hanzel test of linear trend,  $p < 0.001$ ). Similarly, persons with increased functional decline were more likely to die at home (Table 2).

COMMENTARY

Our experience with death, both personally and culturally, has profoundly changed during the

past century.<sup>17</sup> During the early 1900s, the dying trajectory had a sharp decline over a short period of time with the exception of a few long-term infections such as tuberculosis. Now as we enter a new millenium, lifespan continues to increase in the industrialized nations; yet society is increasingly faced with chronic, progressive illnesses that result in prolonged periods of disability.<sup>18</sup> We found that more than 40% of persons dying of DM, CHF, COPD, and CVA had existing ADL impairments 1 year prior to death. Persons dying of

TABLE 2. ASSOCIATION OF FUNCTIONAL TRAJECTORY WITH HOSPICE INVOLVEMENT AND DYING AT HOME

ADL change from 5 months prior to death to day before death	Weighted Number of Decedents	Hospice Involved (%)	Died at Home (%)
No change	491,599	6.5	20.3
1 ADL	73,635	10.2	33.6
2 ADLs	34,923	23.7	37.4
3 or more ADLs	250,211	29.0	40.7

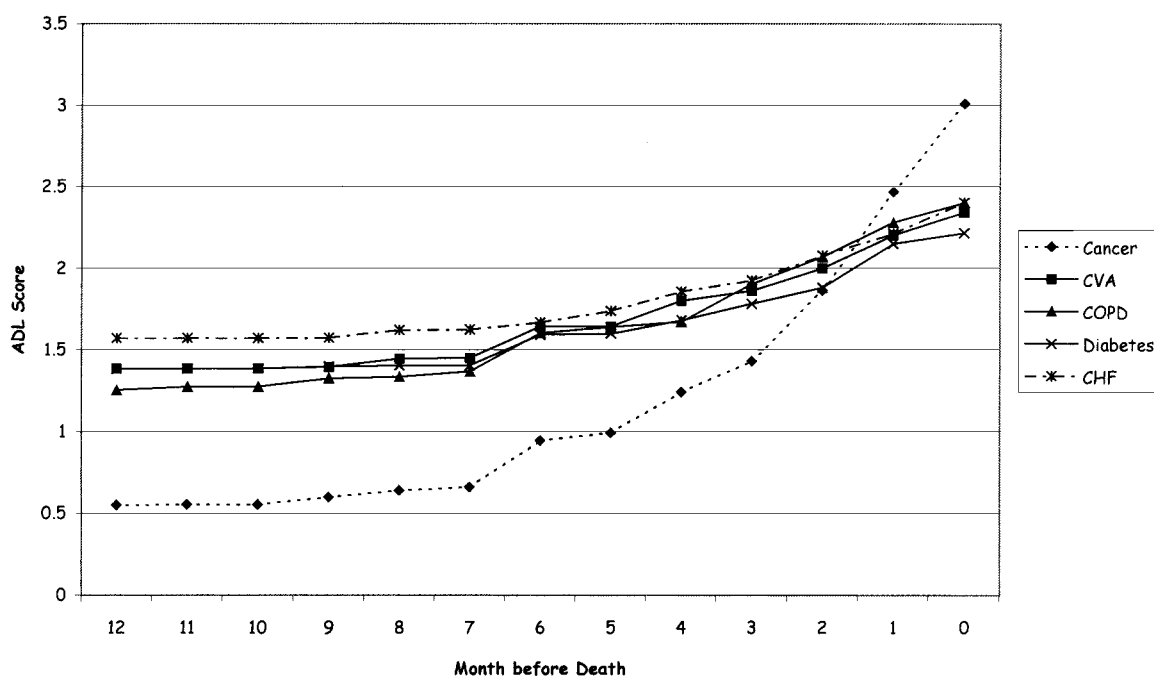


FIG. 1. Age-adjusted activities of daily living (ADL) scores by month before death.

cancer (in contrast to these noncancer decedents) were less functionally impaired 1 year prior to death and continued to be so until the last 2 months of life. As shown in Figure 1, cancer patients experienced a more precipitous decline in ADL, which started approximately 5 months prior to death. Such decline was associated with where the person died and whether hospice was involved in their terminal care.

Recent public debate has focused on issues of access and abuse of the U.S. Medicare Hospice Benefit. Many have worried that hospice provides only limited access of hospice to persons with diagnoses other than cancer, partially because it is so difficult to predict survival in this population. The National Hospice Organization has released clinical guidelines as an aid for which persons should be considered for hospice referral.<sup>6</sup> Attempts to validate these guidelines have raised important concerns regarding their ability to predict death.<sup>4</sup> This uncertainty has taken on even more importance with the Office of Inspector General's increased scrutiny of hospice patients surviving longer than 6 months as potentially fraudulent medical care.<sup>19</sup>

Our findings have implications for both of these public policy concerns. We found hospice referral was related to the pattern of functional decline. Among those persons who lost three or more ADL dependencies in the last 5 months of

life, nearly one in three utilized hospice services. The rapidity of the functional decline may serve as a cue to the physician, patient, and family that the person is dying. Additionally, the functional decline and resulting diminished quality of life may influence dying persons and their family to accept the explicit trade-off of the hospice (i.e., forgoing active treatment for increase supportive care). However, the majority of patients did not exhibit that classic rapid functional deterioration. If this is true, perhaps the recertification process for the U.S. Medicare Hospice Benefit discriminates against those persons with noncancer terminal diagnoses. At each recertification period, a physician must attest to the fact that the patient has an expected 6-month prognosis. Among the evidence that Health Care Financing Administration's fiscal intermediaries look to justify this prognosis is documentation of a functional decline. If recertification is biased against patients with noncancer diagnosis, these patients could be discharged inappropriately from hospice just months or days before death.

The functional decline displayed in Figure 1 may have implications for physicians' ability to state a prognosis of 6 months or less. Fox and colleagues<sup>4</sup> found that when using a narrow window of prognostic certainty for determining whether persons with COPD, CHF, and end-stage liver disease will die in the next 6 months,

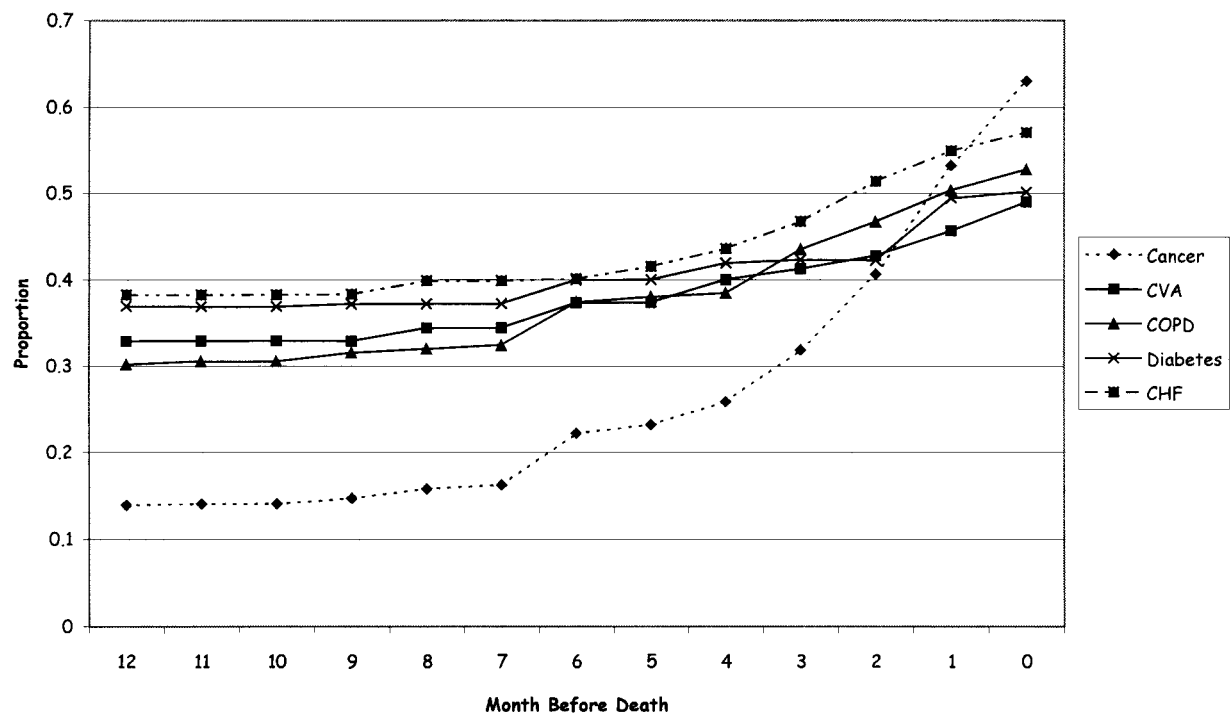


FIG. 2. Adjusted proportion of people with trouble getting in and out of bed or chair.

could severely limit their access to hospice services.<sup>4</sup> The functional trajectory found in these noncancer diagnoses might, in part, explain difficulties with predicting a life expectancy of 6 months, as required by the U.S. Medicare Hospice Benefit. For cancer patients, many died after a decision to stop treatment based on its ineffectiveness or toxicity with progressive tumor

growth and inanition resulting in death. To the contrary, this is rarely the final terminal event for persons with CHF, COPD, CVA, and DM. Rather, the final terminal event is an unpredictable event such as arrhythmia, infection, etc.

There are some important limitations to this study that need to be acknowledged. The National Mortality Followback Survey used proxy

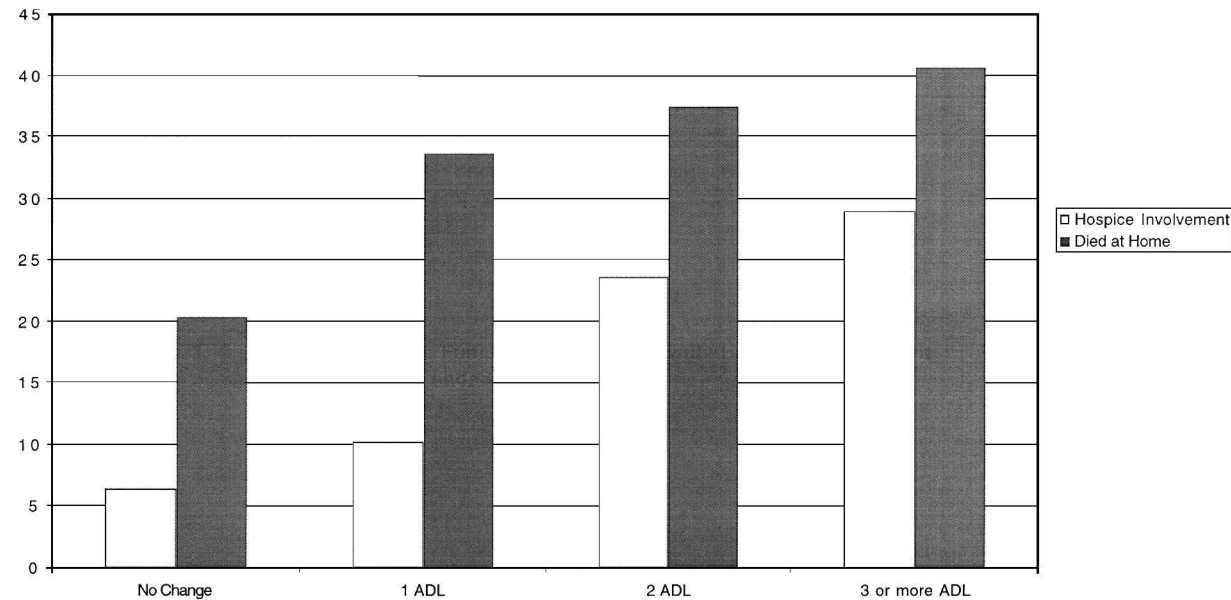


FIG. 3. Association of functional trajectory with hospice involvement and site of death.

interviews, usually asking a close family member or friend, to report the number of days that the decedent had trouble with functioning during their lifetime. A proxy is often the only person able to report on the dying person's ability to function. Many seriously ill and dying persons are often unable to report on their ability to function in the last weeks of life.<sup>20,21</sup> Yet, proxies may be inaccurate in their reporting of the difficulty with functioning. Additionally, this study relies on secondary analyses of existing national data. We are limited to the questions that were asked as part of this survey. For example, questions were not asked about overall quality of life or their satisfaction with life. Finally, our analyses rely on deaths from 1993. A recent study reported decreased functional disability from 1986 to the 1993 Mortality Followback Survey among those persons age 85 and older.<sup>14</sup> While the level of ADL impairments decreased in this age group, more than 50% experienced two or more ADL impairments in the last year of life.

Despite these limitations, the reported results provide the first national estimates of the dying trajectory for cancer and leading noncancer causes of death. Our findings support previous research that supports the notion of dying trajectories and that function declines in the last year of life,<sup>8,11-13</sup> and further finds that the dying trajectory differs between cancer and the leading noncancer causes of death. Future longitudinal, cohort studies are needed to examine patterns of functional decline and quality of life for seriously ill persons further. If such studies confirm these trajectories, public debate needs to reconsider the U.S. Medicare Hospice Benefit. Is it a benefit only for those persons with precipitous functional decline and hence actively dying? Or should we increase access to include persons whose dying trajectories are characterized by prolonged functional impairment and more gradual decline in the last year of life?

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