

Symptom Trends in the Last Year of Life From 1998 to 2010

A Cohort Study

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Background: Calls for improvement in end-of-life care have focused attention on the management of pain and other troubling symptoms at the end of life.

Objective: To describe changes in pain intensity and symptom prevalence during the last year of life from 1998 to 2010.

Design: Observational study.

Setting: The HRS (Health and Retirement Study), a nationally representative longitudinal survey of community-dwelling U.S. residents aged 51 years or older.

Participants: 7204 HRS participants who died while enrolled in the study and their family respondents.

Measurements: Proxy-reported pain during the last year of life and other symptoms for at least 1 month during the last year of life. Trends in pain intensity and symptom prevalence were analyzed for all decedents and within the categories of sudden death, cancer, congestive heart failure or chronic lung disease, and frailty.

Results: Between 1998 and 2010, proxy reports of the prevalence of any pain increased for all decedents from 54.3% (95%

CI, 51.6% to 57.1%) to 60.8% (CI, 58.2% to 63.4%), an increase of 11.9% (CI, 3.1% to 21.4%). Reported prevalences of depression and periodic confusion also increased for all decedents by 26.6% (CI, 14.5% to 40.1%) and 31.3% (CI, 18.6% to 45.1%), respectively. Individual symptoms increased in prevalence among specific decedent categories, except in cancer, which showed no significant changes. The prevalence of moderate or severe pain did not change among all decedents or in any specific decedent category.

Limitation: Use of proxy reports and limited information about some patient and surrogate variables.

Conclusion: Despite national efforts to improve end-of-life care, proxy reports of pain and other alarming symptoms in the last year of life increased from 1998 to 2010.

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In a seminal 1997 report on the state of end-of-life care, the Institute of Medicine described extensive patient and family suffering and emphasized the need for better care at the end of life (1). Subsequent activity included the development of guidelines and quality measures and the growth of palliative medicine, including clinical training programs (2-5). Policy and practice emphasized better pain management (6). Hospice use doubled from 2000 to 2009, with 42% of Americans receiving hospice care before death in 2009 (7).

Symptoms are among the most distressing aspects of the end-of-life experience for patients and families; interventions often promote comfort across a range of conditions and symptoms (2, 8-11). Although we lack definitive population-based data, systematic reviews have shown the high prevalence of many symptoms, including pain, dyspnea, and depression, across many advanced diseases (12). Pain is one of the most prevalent and troubling symptoms, and patients and families fear it and wish to avoid it near the end of life (13, 14).

It is not known whether national efforts to improve end-of-life care since the Institute of Medicine report have led to changes in the prevalence of commonly occurring end-of-life symptoms. We therefore examined nationally representative trends in end-of-life symptom prevalence from 1998 to 2010 for the whole population and for different groups of decedents. Given the strength of practice evidence and policy attention to both cancer and pain (6, 15), we expected

that overall trends would be better for patients with cancer than for those with other conditions, and that trends in the prevalence and severity of pain would be better than for other symptoms.

METHODS

Setting and Study Participants

We used data from the HRS (Health and Retirement Study), a nationally representative longitudinal survey of community-dwelling adults aged 51 years or older in the contiguous United States (16, 17). The mortality rate of the HRS population is similar to that of the overall U.S. population of adults aged 51 years or older. The HRS participants are interviewed every 2 years until their deaths. After each participant's death, study staff interview a proxy informant (typically a family member) who is most familiar with the health, family, and financial situation of the participant. We included participants who died while enrolled in the HRS and whose

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EDITORS' NOTES**Context**

Although end-of-life care has received increased attention, whether symptom management for dying patients has improved is not known.

Contribution

Reports from patients and their proxies before or after death indicated that troubling symptoms remained prevalent, and in some cases increased, between 1998 and 2010.

Caution

Whether differences in patients, proxies, or the focus on reporting symptoms have changed during the time studied is not known.

Implication

Continued focus is required to better address the symptoms of dying patients.

proxy informant provided a postmortem interview within 2 years of death.

Symptom Outcomes

We evaluated symptom prevalence using 8 yes/no questions that asked about the presence of pain, depression, periodic confusion, dyspnea, severe fatigue, incontinence, anorexia, and frequent vomiting. Questions for all symptoms except pain asked whether the decedent had the symptom for at least 1 month during the last year of life. For pain, the question asked whether the decedent was often troubled with pain in the last year of life. In addition, a follow-up question asked about the degree of the pain (mild, moderate, or severe), if present. We analyzed any pain and moderate or severe pain separately. **Appendix Table 1** (available at www.annals.org) provides the exact wording for all symptom questions.

Symptom Covariates

We used a model of whole-person distress, which included demographic characteristics and clinical, psychological, and social domains, and which we modified to include proxy factors. Demographic characteristics included age at death, sex, and race or ethnicity. Clinical covariates included the number of nights spent in a hospital in the last 2 years of life, nursing home residency at the time of death, length of nursing home residency before death (regardless of site of death), number of dependencies in activities of daily living (dressing, walking, bathing, eating, transferring, and toileting), and diagnosis of arthritis (included in models for pain only). The psychological covariate was depression reported in the interview wave before death, which was defined as a score of 4 or greater on an 8-item subset of the 20-item Center for Epidemiologic Studies Depression Scale (18, 19). The social covariates included highest education level, household wealth, and

household income. Proxy covariates included the relationship of the proxy to the decedent (spouse, son or daughter, or other); time elapsed between the decedent's death and the proxy's interview; average hours of care given per week to the decedent from all informal caregivers, including by the proxy; highest education level (only available if the proxy was the decedent's spouse [approximately 33% of proxies]); and English or Spanish preference for the interview. We also included the year that the decedent entered the HRS sample.

Decedent Categories

We used a sequential categorization scheme based on prior work to place decedents into 4 mutually exclusive categories: sudden death, cancer, congestive heart failure (CHF) or chronic lung disease, and frailty (20–23). Decedents were categorized as “sudden death” if they died within 1 day of receiving their terminal diagnosis; “cancer” if their proxy reported cancer as the cause of death; “CHF or chronic lung disease” if they or their proxy reported a diagnosis of either or both of these conditions; or “frailty” if they died in a nursing home, they or their proxy reported physician-diagnosed memory impairment, or their proxy reported hip fracture in the last 2 years of life.

Questions about diagnoses of CHF, chronic lung disease, and physician-diagnosed memory impairment were presented to proxies in postmortem interviews and to decedents in each survey wave while they were alive. We considered each condition to be present if either the decedent or the proxy reported its presence.

Statistical Analysis

All analyses accounted for complex survey design by using sampling weights, which provided estimates representative of the entire U.S. population. We used multivariable logistic regression models to investigate the association between each symptom outcome and time of death. We used 2 sets of models for each outcome: a fully adjusted model that included all symptom covariates previously described, and a minimally adjusted model that included only demographic characteristics and time elapsed between the decedent's death and the proxy's interview. We conducted all analyses for the cohort as a whole and in each of the 4 mutually exclusive decedent categories. All decedents were included in the entire population analysis, and decedents who were placed into 1 of the 4 categories were also analyzed separately in that category.

We report the adjusted prevalence of each symptom by year of death from the fully and minimally adjusted models. The percentage of change in the adjusted prevalence of each symptom was estimated by using the first and last dates of death from all regressions, and bootstrapping with bias correction was used to estimate CIs (24). We report the adjusted percentage of change in the prevalence of each symptom from the fully and minimally adjusted models.

Symptom outcomes were missing for 0.1% (frequent vomiting) to 3.3% (pain) of decedents. Eleven symptom covariates were incompletely reported, with rates of missing outcomes ranging from 0.0006% (diag-

nosis of arthritis) to 8.1% (number of nights spent in a hospital in the last 2 years of life). We used the `ice` command in Stata/IC, version 12.1 (StataCorp) (25), to impute missing values through multiple imputation by chained equations with 15 imputed data sets; we analyzed imputed data with the `mi estimate` commands in Stata/IC or manually by using the Rubin rules (26). We constructed a multiple imputation model that included time of death, decedent categories, all symptom outcome variables, and all symptom covariates described earlier except the year that the decedent entered the HRS sample. Two sets of variables were imputed in forms different from those included in the regression analyses. First, pain was captured with 1 categorical variable that recorded no pain or mild, moderate, or severe pain, and the outcomes of any pain and moderate or severe pain were created from this categorical variable after imputation. Second, the 6 activities of daily living questions were included separately in the imputation model and combined into a scale after imputation.

In the 2002 survey wave only, approximately 41% of the proxies were erroneously not asked nonpain symptom questions because of faulty survey logic. On discovering the issue, staff corrected the survey logic but did not go back and collect the missing data. As a result, those responses were permanently lost. In our primary analyses, we excluded proxies in the 2002 survey wave with missing symptom questions. In a sensitivity analysis, we replicated these analyses after excluding the entire 2002 survey wave to investigate the effect of potentially nonrandom missing data due to faulty survey logic.

We also performed an additional sensitivity analysis to evaluate whether there was substantial year-to-year variation in our outcomes. We replicated each minimally adjusted multivariable logistic regression using a continuous variable that captured each survey year rather than a variable that captured time of death. We report the average yearly percentage of change and CIs.

We conducted all analyses with Stata/IC, version 12.1. The RAND Institutional Review Board approved the study.

Role of the Funding Source

The National Institute of Nursing Research supported this research but had no role in the design, conduct, or analysis of the study or the decision to submit the manuscript for publication.

RESULTS

From 1998 to 2010, a total of 8641 HRS participants died and 8089 proxy interviews were completed. Of those, 7204 interviews were completed within 2 years of the decedent's death; these were included in our study cohort. The response rates for the 6 survey waves from 2000 to 2010 were 86%, 85%, 91%, 88%,

92%, and 85%, respectively. Table 1 presents the weighted characteristics of the cohort as a whole and by time of death. The mean age at death was 79.1 years, 54% were women, and 17% were nonwhite. Twenty-two percent were reported to have had cancer, 33% had CHF or chronic lung disease, 16% were frail, and 16% died suddenly. Fourteen percent reported none of these categories. Approximately 50% of decedents were reported to have had moderate or severe pain, depression, periodic confusion, dyspnea, or incontinence; approximately 60% were reported to have had any pain, severe fatigue, or anorexia; and approximately 12% were reported to have had frequent vomiting.

Table 2 presents the adjusted prevalence of symptoms from the fully and minimally adjusted models for all decedents between 1998 and 2010; Appendix Tables 2 and 3 (available at www.annals.org) present this information for cancer, CHF or chronic lung disease, frailty, and sudden death. These estimates are largely similar between the 2 sets of models and show the high prevalence of most symptoms in the entire population and all decedent categories. Most estimates also suggest positive trends in prevalence over time.

Table 3 presents the adjusted percentage of change in the prevalence of symptoms from the fully and minimally adjusted models for all decedents and for decedents in the categories of cancer, CHF or chronic lung disease, frailty, or sudden death. In the fully adjusted models, proxy reports of the prevalence of any pain (mild, moderate, or severe) increased for all decedents by 11.9% (95% CI, 3.1% to 21.4%) between 1998 and 2010. Reported prevalences of depression and periodic confusion increased for all decedents and in certain decedent categories. The prevalence of incontinence also increased for all decedents. Increasing trends in the reported prevalence of other symptoms were seen in most decedent categories but were not significant. Moderate or severe pain, severe fatigue, anorexia, and frequent vomiting did not show significant changes in any group of decedents, and there were no significant changes for cancer.

As compared with the fully adjusted models, the minimally adjusted models generally showed a larger percentage of changes in the prevalence of symptoms, and more of these changes were significant (Table 3). As with the fully adjusted models, there were no significant changes for cancer.

We performed 2 sensitivity analyses for the fully adjusted models: one to estimate symptom prevalence and percentage of change with the 2002 survey wave excluded (Appendix Tables 4 and 5, available at www.annals.org) and the other to investigate yearly changes rather than 12-year changes (Appendix Table 6, available at www.annals.org). The overall results did not differ appreciably between analyses with and without the 2002 survey wave, and the magnitude and significance of the yearly changes generally comported with those of the 12-year changes.

Table 1. Characteristics of the Study Population, by Interval of Death*

Characteristic	Decedents		
	Total (n = 7204)	1998-2000 (n = 1243)	2000-2002 (n = 1226)
Age at death			
<65 y	12.3	13.7	10.4
65-74 y	19.6	20.4	21.2
75-84 y	32.6	33.0	33.2
>84 y	35.5	32.9	35.2
Female	53.6	51.3	53.0
Ethnicity			
Non-Hispanic white	83.2	84.4	82.3
Non-Hispanic black	10.3	10.3	10.7
Hispanic	4.6	3.7	4.9
Other	1.9	1.6	2.1
Decedent categories			
Cancer	22.2	23.8	21.8
CHF or chronic lung disease	32.5	27.7	30.9
Frailty	15.5	14.5	15.0
Sudden death	15.7	18.7	14.9
Symptoms			
Moderate or severe pain	50.6	46.7	47.7
Any pain	57.5	53.1	53.9
Depression	51.4	44.6	49.5
Periodic confusion	47.9	41.7	42.8
Dyspnea	52.6	49.8	51.9
Incontinence	45.8	41.9	43.2
Severe fatigue	62.4	59.2	57.9
Anorexia	64.0	62.1	61.1
Frequent vomiting	11.8	11.4	11.4
Comorbid conditions			
Depression	26.4	25.9	27.8
Arthritis	67.6	57.8	65.3
≥2 ADL dependencies†	70.6	66.8	67.8
Health care utilization			
Median nights in hospital in last 2 y of life (IQR), n	7 (0-20)	5 (0-19)	7 (0-21)
Nursing home residency at time of death	28.0	28.8	29.9
Median informal care received per week in last 2 y of life (IQR), h	15 (0-93)	13 (0-75)	16 (0-90)
Highest education level			
Some high school or less	55.4	60.2	60.3
High school graduate	29.4	27.8	26.2
Some college or more	15.2	12.1	13.5
Median household wealth (IQR), \$	83 000 (8000-273 000)	72 000 (7000-209 000)	81 000 (8000-220 000)
Median annual household income (IQR), \$	20 000 (11 000-36 000)	17 000 (10 000-32 000)	18 000 (10 000-34 000)
Relationship of proxy to decedent			
Spouse	32.9	34.0	33.7
Son or daughter	44.8	42.9	41.9
Other	22.3	23.1	24.4
Mean time between decedent's death and proxy's interview (95% CI), mo	11.3 (11.1-11.5)	11.5 (11.1-11.9)	12.6 (12.1-13.0)
Spouse's highest education level‡			
Some high school or less	43.4	42.4	45.4
High school graduate	37.1	41.0	36.7
Some college or more	19.5	16.6	17.9
Interview conducted in English	98.3	98.4	98.2

ADL = activities of daily living; CHF = congestive heart failure; IQR = interquartile range.

* Analysis accounts for complex survey design. Values are percentages unless otherwise indicated. Percentages are rounded and may not sum to 100%.

† Dressing, walking, bathing, eating, transferring, or toileting.

‡ If spouse was proxy.

Table 1—Continued

Decedents			
2002-2004 (n = 1144)	2004-2006 (n = 1186)	2006-2008 (n = 1212)	2008-2010 (n = 1193)
7.8	14.6	14.6	12.0
18.1	18.3	18.5	21.3
39.1	31.5	30.4	29.2
35.0	35.6	36.5	37.5
54.4	51.4	55.9	55.4
83.7	81.9	83.1	83.8
9.9	10.6	10.6	9.9
4.4	4.9	4.7	4.9
2.0	2.7	1.6	1.4
21.2	20.9	22.5	22.9
32.9	34.8	33.5	34.6
15.4	16.1	16.9	14.8
15.7	13.4	16.1	15.7
49.9	51.9	51.5	54.8
56.8	58.7	57.9	63.6
51.8	52.0	53.2	55.5
46.1	49.6	54.1	49.1
52.4	50.9	53.5	56.2
47.6	47.1	46.3	46.8
63.0	66.6	62.7	62.6
62.1	65.0	67.6	64.1
11.5	11.4	13.5	11.1
27.1	25.7	26.1	26.0
70.5	69.0	70.4	71.2
70.5	73.6	71.2	72.7
6 (0-20)	7 (0-21)	7 (0-20)	7 (0-20)
29.2	26.9	29.2	24.2
14 (0-88)	18 (0-106)	14 (0-111)	21 (1-103)
54.1	54.2	52.3	52.5
30.2	30.3	30.4	30.8
15.8	15.5	17.2	16.7
94 000 (8000-259 000)	89 000 (3000-265 000)	83 000 (6000-330 000)	102 000 (8000-336 000)
18 000 (11 000-32 000)	21 000 (12 000-39 000)	21 000 (12 000-38 000)	24 000 (13 000-45 000)
30.3	36.2	31.8	31.3
44.0	43.7	46.5	49.0
25.8	20.1	21.7	19.6
11.0 (10.5-11.5)	10.9 (10.4-11.3)	10.7 (10.2-11.1)	11.5 (11.1-11.9)
44.5	42.2	45.3	41.0
39.7	38.7	33.3	33.5
15.8	19.1	21.4	25.4
98.4	98.2	98.3	98.1

Table 2. Adjusted Estimated Prevalence of Symptoms Between 1998 and 2010 in the Entire Population, by Year of Death*

Outcome	Decedents (95% CI), %						
	1998	2000	2002	2004	2006	2008	2010
Fully adjusted models†							
Moderate or severe pain	48.7 (45.8–51.6)	49.3 (47.0–51.5)	49.9 (48.2–51.6)	50.5 (49.0–52.0)	51.1 (49.5–52.7)	51.7 (49.6–53.8)	52.4 (49.6–55.2)
Any pain	54.3 (51.6–57.1)	55.4 (53.3–57.5)	56.5 (54.9–58.1)	57.5 (56.2–58.9)	58.6 (57.1–60.1)	59.7 (57.7–61.6)	60.8 (58.2–63.4)
Depression	45.0 (42.3–47.7)	47.0 (44.9–49.1)	49.0 (47.3–50.6)	50.9 (49.4–52.4)	52.9 (51.1–54.7)	54.9 (52.5–57.2)	57.0 (53.9–60.0)
Periodic confusion	41.1 (38.5–43.6)	43.2 (41.2–45.2)	45.3 (43.8–46.8)	47.4 (46.3–48.5)	49.5 (48.4–50.7)	51.7 (50.2–53.1)	53.9 (51.9–56.0)
Dyspnea	50.2 (48.1–52.2)	50.9 (49.4–52.5)	51.7 (50.5–52.9)	52.4 (51.3–53.6)	53.2 (51.8–54.6)	54.0 (52.1–55.8)	54.8 (52.3–57.2)
Incontinence	43.0 (40.0–46.0)	43.8 (41.6–46.1)	44.7 (43.1–46.2)	45.5 (44.4–46.7)	46.4 (45.0–47.7)	47.2 (45.2–49.2)	48.1 (45.3–51.0)
Severe fatigue	60.7 (58.0–63.4)	61.2 (59.2–63.2)	61.7 (60.3–63.1)	62.2 (61.0–63.4)	62.7 (61.3–64.1)	63.2 (61.2–65.1)	63.7 (61.0–66.4)
Anorexia	62.2 (59.5–64.9)	62.7 (60.7–64.7)	63.2 (61.8–64.6)	63.8 (62.5–65.0)	64.3 (62.7–65.9)	64.8 (62.5–67.1)	65.4 (62.3–68.4)
Frequent vomiting	12.3 (10.4–14.2)	12.1 (10.7–13.5)	11.9 (10.9–12.9)	11.7 (11.0–12.5)	11.6 (10.8–12.4)	11.4 (10.3–12.5)	11.2 (9.7–12.7)
Minimally adjusted models‡							
Moderate or severe pain	45.7 (42.9–48.5)	47.3 (45.1–49.4)	48.8 (47.1–50.6)	50.4 (48.8–52.0)	52.0 (50.2–53.8)	53.6 (51.2–55.9)	55.3 (52.3–58.3)
Any pain	51.5 (48.8–54.1)	53.5 (51.4–55.5)	55.5 (53.9–57.1)	57.5 (56.0–59.0)	59.5 (57.7–61.2)	61.4 (59.1–63.7)	63.4 (60.6–66.3)
Depression	44.7 (42.2–47.2)	46.8 (44.9–48.7)	48.8 (47.3–50.4)	50.9 (49.4–52.5)	53.0 (51.1–54.9)	55.0 (52.6–57.5)	57.2 (54.1–60.4)
Periodic confusion	41.6 (38.9–44.3)	43.5 (41.4–45.6)	45.5 (43.9–47.1)	47.5 (46.2–48.7)	49.5 (48.1–50.8)	51.4 (49.6–53.3)	53.6 (51.1–56.1)
Dyspnea	49.2 (47.1–51.3)	50.3 (48.7–51.8)	51.3 (50.1–52.6)	52.4 (51.2–53.6)	53.4 (51.9–55.0)	54.5 (52.5–56.5)	55.6 (53.0–58.3)
Incontinence	43.3 (40.4–46.2)	44.1 (42.0–46.2)	44.8 (43.4–46.3)	45.6 (44.4–46.7)	46.3 (44.8–47.8)	47.0 (44.8–49.3)	47.8 (44.8–50.9)
Severe fatigue	59.5 (56.7–62.4)	60.4 (58.4–62.5)	61.3 (59.8–62.7)	62.1 (60.9–63.4)	63.0 (61.4–64.6)	63.8 (61.6–66.1)	64.7 (61.7–67.7)
Anorexia	61.0 (58.4–63.7)	61.9 (60.0–63.9)	62.8 (61.4–64.3)	63.7 (62.3–65.1)	64.6 (62.8–66.3)	65.4 (63.1–67.7)	66.3 (63.3–69.4)
Frequent vomiting	11.4 (9.6–13.2)	11.5 (10.1–12.8)	11.6 (10.6–12.6)	11.7 (10.9–12.4)	11.8 (11.0–12.6)	11.9 (10.8–13.0)	12.0 (10.4–13.5)

* Analysis accounts for complex survey design.

† Adjusted prevalence was estimated from regression models of each symptom on time of death, with control for age at death, sex, race/ethnicity, number of nights spent in a hospital in the last 2 y of life, nursing home residency at the time of death and length of nursing home residency before death (regardless of site of death), number of activities of daily living dependencies (dressing, walking, bathing, eating, transferring, or toileting), diagnosis of arthritis (pain models only), depression reported in interview wave before death, highest education level, household wealth, annual household income, proxy's relationship to decedent, time elapsed between decedent's death and proxy's interview, average hours of care per week given to decedent from all informal caregivers, spouse's highest education level if proxy was spouse, English/Spanish preference for interview, and year that the decedent entered the Health and Retirement Study sample.

‡ Adjusted prevalence was estimated from regression models of each symptom on time of death, with control for age at death, sex, race/ethnicity, and time elapsed between decedent's death and proxy's interview.

DISCUSSION

We analyzed interviews with bereaved family members conducted on behalf of decedents in a large, nationally representative survey to evaluate changes in end-of-life symptom burden in the United States between 1998 and 2010. Over the time frame of our study, proxy reports of many symptoms increased in prevalence, including pain, depression, and periodic confusion. Consistent with our hypothesis, we found no significant trends in any symptom among decedents with cancer.

Proxy reports of worsening symptom prevalence raise concerns about shortcomings in end-of-life care despite increasing national attention and resources devoted to it. Indeed, recent studies of health care performance suggest that persistent gaps remain in addressing symptoms near the end of life (27–29). It is particularly concerning that proxy reports of pain have increased because pain is among the most visible and well-studied aspects of the end-of-life experience, has received policy attention, and significantly affects health-related quality of life (6). Moderate and severe pain, for example, have a more pronounced effect on health-related quality of life than many health and sociodemographic factors (30, 31). It is encouraging, however, that trends in the prevalence and severity of cancer pain may have stabilized. This should be monitored in the face of growing public concern about pre-

scription opioid abuse, which may create resistance to opioid use from clinicians and patients in otherwise-appropriate scenarios (32).

Our results indicate that symptom burden is high near the end of life, and our findings are generally concordant with those of population-level studies from other countries. Outpatients with cancer in Canada assessed between diagnosis and death reported prevalences of 45% to 60% for pain, dyspnea, depression, and anorexia, and 75% for fatigue (33). Dyspnea prevalence among hospice patients in Australia at 3 months before death was 50% overall, 65% for patients with heart failure, and 88% for those with end-stage pulmonary disease (34).

Many factors might contribute to the persistence and potential increase in prevalence of these troubling end-of-life symptoms. Recent reports show that the intensity of treatment and the rate of adverse transitions have been increasing near the end of life (7). Hospice is often "tacked on" to this more intense late-life care: Although hospice use doubled from 2000 to 2009, the median stay is less than 3 weeks (7, 35). Some patients who have short stays may not realize the full benefits of hospice for symptomatic relief. Palliative care services are more common in hospitals, and patients may not have consistent access to palliative services in outpatient, home, and long-term facility settings where most of the course of a terminal illness takes place. Effective

interventions can sometimes mitigate the symptoms we have highlighted (for example, opioid regimens for pain and dyspnea) (36), but significant gaps remain in their delivery near the end of life (37, 38). Therefore, interventions may not be reaching the right patients in the right ways.

In addition, increased attention to end-of-life care in general and symptoms specifically may have increased proxy reporting of symptoms over the time frame of our study. For example, if clinicians became more likely to ask about symptoms, proxies may have become more aware of them and thus more likely to report them.

Proxy reports inevitably reflect both the patient's and the proxy's experiences. They can provide invaluable information, but further research is needed to improve their validity, particularly with regard to the reporting of subjective symptoms, which proxies tend to overestimate (39). The evidence base is inconsistent with respect to the effect of various factors on the validity of proxy reports, including the contributions of caregiver distress and the proxy's relationship to the decedent (39). Improved understanding of proxy reports is especially important now that they are being used in hospice and other settings for quality assessment and improvement (40).

We faced several limitations. First, we used proxy reports of outcomes, which could affect the validity of

subjective symptoms (39). Second, we used mostly yes/no questions, which might have masked variation in symptom intensity. Although we could not assess changes in the severity of nonpain outcomes, the increase in their reported prevalence raises concerns. Third, because of limitations in the survey itself, we could not capture all constructs relevant to evaluating symptom trends in end-of-life patients, particularly hospice enrollment and site of death. The attenuation of many of our results in fully adjusted models compared with minimally adjusted models suggests that changes in many of the proxy and decedent characteristics were partially responsible for the changes in reported symptoms we observed. It is therefore important to recognize that residual confounding may remain because of other factors we could not account for in our models.

In summary, between 1998 and 2010, proxy reports of serious pain and many other distressing symptoms became more common near the end of life. Given our knowledge of best practices and continued gaps in applying them, there is an urgent need to benchmark current practice against current knowledge. Future research should evaluate settings that provide better and worse end-of-life symptom management to offer insight into promoting best practices. Improving care at the end of life will necessitate further investment to understand the trends we identified, and steps will be required to reverse them.

Table 3. Adjusted Total Percentage of Change in Prevalence of Symptoms Between 1998 and 2010*

Outcome	Adjusted Change (95% CI), %†				
	Entire Population (n = 7204)	Cancer (n = 1546)	CHF or Chronic Lung Disease (n = 2293)	Frailty (n = 1175)	Sudden Death (n = 1161)
Fully adjusted models‡					
Moderate or severe pain	7.6 (−1.9 to 18.4)	4.8 (−10.9 to 24.0)	4.2 (−10.6 to 23.3)	6.8 (−21.8 to 43.9)	−3.0 (−26.2 to 28.5)
Any pain	11.9 (3.1 to 21.4)	7.9 (−6.7 to 25.5)	12.0 (−2.0 to 29.0)	12.4 (−13.3 to 45.5)	8.0 (−13.9 to 35.7)
Depression	26.6 (14.5 to 40.1)	8.8 (−11.6 to 33.4)	27.0 (8.1 to 49.3)	39.4 (9.9 to 79.8)	17.0 (−10.4 to 53.0)
Periodic confusion	31.3 (18.6 to 45.1)	26.3 (−1.6 to 61.1)	24.9 (6.0 to 47.6)	20.3 (5.9 to 39.1)	45.7 (5.9 to 106.1)
Dyspnea	9.2 (−1.0 to 19.9)	4.4 (−15.8 to 27.0)	0.5 (−8.7 to 11.8)	8.9 (−28.1 to 56.2)	36.7 (2.3 to 85.9)
Incontinence	11.9 (1.0 to 23.6)	−4.4 (−26.1 to 21.7)	10.0 (−7.2 to 30.5)	2.8 (−14.1 to 21.7)	29.3 (−5.1 to 82.4)
Severe fatigue	4.9 (−2.9 to 13.7)	7.0 (−5.5 to 21.4)	−2.3 (−13.2 to 10.6)	−1.8 (−22.1 to 25.4)	16.4 (−10.5 to 51.7)
Anorexia	5.1 (−2.4 to 13.2)	7.4 (−3.7 to 18.8)	0.8 (−10.6 to 13.7)	−7.5 (−23.2 to 10.4)	13.9 (−16.4 to 50.3)
Frequent vomiting	−8.8 (−31.2 to 21.5)	11.4 (−26.0 to 72.8)	−30.5 (−60.2 to 26.8)	−26.4 (−66.0 to 69.4)	72.5 (−30.4 to 305.7)
Minimally adjusted models§					
Moderate or severe pain	20.9 (9.7 to 32.9)	11.2 (−5.8 to 31.2)	15.9 (−1.3 to 37.0)	13.3 (−16.6 to 53.9)	24.3 (−6.6 to 66.4)
Any pain	23.3 (13.4 to 33.9)	13.0 (−2.6 to 31.3)	22.5 (7.0 to 41.7)	18.4 (−8.5 to 55.2)	32.8 (5.3 to 68.9)
Depression	28.0 (15.7 to 42.0)	11.5 (−9.8 to 36.7)	25.0 (6.4 to 46.7)	37.6 (8.2 to 78.0)	23.1 (−7.8 to 64.6)
Periodic confusion	28.8 (15.6 to 43.6)	26.7 (−2.4 to 61.5)	16.5 (−2.4 to 39.0)	20.1 (5.0 to 39.0)	49.4 (3.4 to 114.8)
Dyspnea	13.1 (2.5 to 24.5)	5.0 (−15.4 to 27.9)	2.5 (−7.0 to 13.1)	9.1 (−26.2 to 56.1)	42.4 (6.6 to 92.6)
Incontinence	10.4 (−0.6 to 23.3)	−9.9 (−29.6 to 16.6)	3.0 (−14.4 to 23.4)	−1.9 (−18.7 to 16.8)	48.2 (4.9 to 113.5)
Severe fatigue	8.7 (0.3 to 17.6)	3.4 (−8.8 to 17.7)	0.7 (−10.8 to 14.1)	−2.2 (−23.1 to 24.3)	21.3 (−6.6 to 59.3)
Anorexia	8.7 (0.5 to 17.5)	8.1 (−3.3 to 20.4)	1.2 (−10.5 to 14.3)	−6.0 (−21.9 to 12.0)	21.2 (−11.6 to 63.9)
Frequent vomiting	5.1 (−20.8 to 40.3)	25.7 (−16.9 to 91.4)	−29.4 (−60.9 to 27.2)	−16.3 (−63.2 to 93.6)	105.5 (−13.9 to 457.9)

CHF = congestive heart failure.

* Analysis accounts for complex survey design.

† 1029 decedents did not qualify for placement in any of the 4 categories.

‡ Adjusted percentage of change was estimated from regression models of each symptom on time of death, with control for age at death, sex, race/ethnicity, number of nights spent in a hospital in the last 2 y of life, nursing home residency at the time of death and length of nursing home residency before death (regardless of site of death), number of activities of daily living dependencies (dressing, walking, bathing, eating, transferring, or toileting), diagnosis of arthritis (pain models only), depression reported in interview wave before death, highest education level, household wealth, annual household income, proxy's relationship to decedent, time elapsed between decedent's death and proxy's interview, average hours of care per week given to decedent from all informal caregivers, spouse's highest education level if proxy was spouse, English/Spanish preference for interview, and year that the decedent entered the Health and Retirement Study sample. CIs are bootstrapped.

§ Adjusted percentage of change was estimated from regression models of each symptom on time of death, with control for age at death, sex, race/ethnicity, and time elapsed between decedent's death and proxy's interview. CIs are bootstrapped.

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Appendix Table 1. HRS Survey Questions Used to Construct Symptom Outcomes

Outcome	HRS Variable	Question to Proxy
Presence of pain	C104	Was [he/she] often troubled with pain? We want a general idea of [his/her] pain level during the last year or so of life.
Degree of pain	C105	How bad was the pain most of the time: mild, moderate, or severe?
Dyspnea	C198	Was there a period of at least 1 month during the last year of [his/her] life when [he/she] had difficulty breathing?
Anorexia	C199	Was there a period of at least 1 month during the last year of [his/her] life when [he/she] had very little appetite or desire for food?
Frequent vomiting	C200	Was there a period of at least 1 month during the last year of [his/her] life when [he/she] had frequent vomiting?
Depression	C202	Was there a period of at least 1 month during the last year of [his/her] life when [he/she] had depression?
Periodic confusion	C203	Was there a period of at least 1 month during the last year of [his/her] life when [he/she] had periodic confusion?
Severe fatigue	C204	Was there a period of at least 1 month during the last year of [his/her] life when [he/she] had severe fatigue or exhaustion?
Incontinence	C208	Was there a period of at least 1 month during the last year of [his/her] life when [he/she] had loss of control of bowel or bladder?

HRS = Health and Retirement Study.

Appendix Table 2. Adjusted Estimated Prevalence of Symptoms Between 1998 and 2010 Among Decedent Categories, by Year of Death: Fully Adjusted Models*

Outcome, by Category	Decedents (95% CI), %†							
	1998	2000	2002	2004	2006	2008	2010	
Cancer								
Moderate or severe pain	60.3 (54.4–66.2)	60.8 (56.5–65.1)	61.3 (58.1–64.5)	61.8 (58.8–64.7)	62.2 (58.5–66.0)	62.7 (57.5–67.9)	63.2 (56.3–70.1)	
Any pain	63.7 (57.8–69.6)	64.6 (60.3–68.9)	65.4 (62.4–68.4)	66.2 (63.7–68.8)	67.1 (64.0–70.2)	67.9 (63.6–72.2)	68.7 (62.9–74.6)	
Depression	51.1 (46.3–56.0)	51.9 (48.3–55.5)	52.6 (49.8–55.4)	53.3 (50.4–56.3)	54.1 (50.3–57.9)	54.8 (49.7–59.9)	55.6 (48.9–62.3)	
Periodic confusion	38.1 (33.0–43.2)	39.7 (35.9–43.6)	41.4 (38.5–44.3)	43.0 (40.3–45.7)	44.7 (41.3–48.0)	46.3 (41.7–50.9)	48.1 (42.0–54.3)	
Dyspnea	52.8 (48.0–57.5)	53.2 (49.5–56.8)	53.5 (50.6–56.5)	53.9 (51.0–56.8)	54.3 (50.7–57.9)	54.7 (50.0–59.3)	55.1 (49.1–61.1)	
Incontinence	43.0 (38.1–47.9)	42.7 (38.8–46.6)	42.4 (39.3–45.5)	42.1 (39.1–45.0)	41.8 (38.4–45.1)	41.5 (37.2–45.7)	41.1 (35.7–46.6)	
Severe fatigue	75.5 (69.7–81.2)	76.4 (72.3–80.5)	77.3 (74.7–80.0)	78.2 (76.2–80.2)	79.1 (76.6–81.6)	79.9 (76.3–83.5)	80.8 (75.8–85.7)	
Anorexia	77.3 (72.9–81.7)	78.4 (75.1–81.6)	79.4 (76.9–81.8)	80.3 (78.0–82.6)	81.2 (78.5–84.0)	82.1 (78.6–85.7)	83.1 (78.6–87.5)	
Frequent vomiting	20.7 (15.3–26.0)	21.0 (16.9–25.2)	21.4 (18.3–24.6)	21.8 (19.3–24.3)	22.2 (19.6–24.8)	22.6 (19.1–26.1)	23.0 (18.2–27.8)	
CHF or chronic lung disease								
Moderate or severe pain	52.4 (47.7–57.1)	52.8 (49.2–56.3)	53.1 (50.5–55.7)	53.5 (51.3–55.6)	53.8 (51.4–56.3)	54.2 (50.9–57.6)	54.6 (50.0–59.1)	
Any pain	57.3 (53.4–61.2)	58.5 (55.5–61.5)	59.6 (57.3–61.9)	60.8 (58.7–62.8)	61.9 (59.4–64.3)	63.0 (59.9–66.1)	64.2 (60.1–68.2)	
Depression	50.0 (45.2–54.9)	52.3 (48.5–56.1)	54.6 (51.7–57.5)	56.8 (54.4–59.3)	59.0 (56.4–61.7)	61.2 (57.9–64.5)	63.5 (59.3–67.8)	
Periodic confusion	45.0 (40.5–49.5)	46.8 (43.4–50.3)	48.7 (46.1–51.3)	50.6 (48.4–52.7)	52.4 (50.1–54.7)	54.2 (51.2–57.3)	56.2 (52.1–60.3)	
Dyspnea	75.1 (70.8–79.4)	75.1 (71.9–78.4)	75.2 (72.8–77.6)	75.3 (73.4–77.2)	75.3 (73.2–77.4)	75.4 (72.6–78.2)	75.5 (71.6–79.3)	
Incontinence	46.6 (41.9–51.3)	47.4 (43.9–50.9)	48.2 (45.6–50.7)	48.9 (47.0–50.9)	49.7 (47.6–51.8)	50.5 (47.5–53.4)	51.3 (47.2–55.4)	
Severe fatigue	69.3 (65.1–73.6)	69.1 (65.8–72.3)	68.8 (66.4–71.2)	68.5 (66.5–70.6)	68.3 (65.9–70.6)	68.0 (64.8–71.2)	67.7 (63.4–72.0)	
Anorexia	68.7 (63.8–73.5)	68.8 (65.0–72.5)	68.9 (66.0–71.7)	68.9 (66.6–71.3)	69.0 (66.5–71.6)	69.1 (65.8–72.4)	69.2 (64.8–73.6)	
Frequent vomiting	12.1 (8.5–15.6)	11.4 (8.9–13.9)	10.7 (9.0–12.4)	10.1 (8.8–11.4)	9.5 (8.1–11.0)	9.0 (7.0–10.9)	8.4 (5.8–11.0)	
Frailty								
Moderate or severe pain	37.7 (30.3–45.0)	38.1 (32.6–43.6)	38.5 (34.7–42.4)	38.9 (36.1–41.8)	39.4 (36.1–42.6)	39.8 (35.1–44.5)	40.2 (33.6–46.9)	
Any pain	43.9 (37.2–50.6)	44.8 (39.5–50.0)	45.7 (41.6–49.7)	46.6 (43.3–49.9)	47.5 (44.1–50.8)	48.4 (44.2–52.6)	49.3 (43.8–54.9)	
Depression	42.3 (35.8–48.8)	45.0 (39.9–50.1)	47.8 (43.9–51.6)	50.6 (47.5–53.6)	53.3 (50.2–56.4)	56.1 (52.1–60.0)	59.0 (53.6–64.3)	
Periodic confusion	69.3 (62.0–76.5)	71.9 (66.6–77.3)	74.5 (70.6–78.4)	76.9 (73.9–79.9)	79.1 (76.3–82.0)	81.2 (77.9–84.6)	83.3 (79.3–87.4)	
Dyspnea	28.8 (22.6–35.1)	29.2 (24.5–34.0)	29.7 (26.3–33.0)	30.1 (27.7–32.5)	30.5 (28.0–33.0)	30.9 (27.4–34.5)	31.4 (26.2–36.6)	
Incontinence	65.3 (59.2–71.4)	65.6 (60.8–70.4)	65.9 (62.1–69.7)	66.2 (63.0–69.4)	66.5 (63.2–69.9)	66.8 (62.7–71.0)	67.2 (61.8–72.5)	
Severe fatigue	52.9 (46.5–59.4)	52.8 (48.0–57.5)	52.6 (49.2–56.1)	52.5 (49.4–55.5)	52.3 (48.4–56.2)	52.1 (46.7–57.6)	52.0 (44.6–59.3)	
Anorexia	68.6 (60.0–77.1)	67.7 (61.3–74.2)	66.9 (62.3–71.5)	66.1 (62.7–69.4)	65.2 (61.5–68.9)	64.3 (58.9–69.7)	63.4 (55.5–71.2)	
Frequent vomiting	7.5 (4.0–11.0)	7.1 (4.7–9.6)	6.8 (5.1–8.5)	6.5 (5.0–7.9)	6.1 (4.3–8.0)	5.8 (3.4–8.3)	5.5 (2.4–8.7)	
Sudden death								
Moderate or severe pain	42.0 (35.1–48.8)	41.8 (36.6–46.9)	41.6 (37.9–45.2)	41.4 (38.6–44.1)	41.2 (38.2–44.1)	40.9 (36.8–45.1)	40.7 (34.9–46.6)	
Any pain	49.0 (42.6–55.4)	49.6 (44.9–54.3)	50.3 (47.0–53.6)	50.9 (48.2–53.6)	51.6 (48.1–55.0)	52.2 (47.3–57.1)	52.9 (46.1–59.7)	
Depression	39.5 (33.8–45.1)	40.5 (36.2–44.9)	41.6 (38.4–44.9)	42.7 (39.8–45.6)	43.8 (40.4–47.3)	45.0 (40.3–49.6)	46.2 (39.9–52.5)	
Periodic confusion	26.0 (20.1–31.9)	27.8 (23.1–32.6)	29.7 (26.1–33.3)	31.7 (29.0–34.3)	33.6 (31.2–36.1)	35.7 (32.4–38.9)	37.9 (33.2–42.7)	
Dyspnea	34.7 (29.6–39.7)	36.7 (32.6–40.7)	38.7 (35.4–42.0)	40.8 (37.7–43.8)	42.9 (39.4–46.4)	45.1 (40.6–49.5)	47.4 (41.6–53.2)	
Incontinence	28.6 (21.8–35.4)	29.9 (24.7–35.1)	31.2 (27.5–35.0)	32.6 (29.9–35.4)	34.0 (31.0–37.0)	35.4 (31.1–39.7)	37.0 (30.7–43.2)	
Severe fatigue	43.4 (37.3–49.6)	44.6 (40.2–49.0)	45.8 (42.8–48.7)	46.9 (44.7–49.2)	48.1 (45.1–51.1)	49.3 (44.7–53.8)	50.5 (44.0–57.0)	
Anorexia	37.8 (32.3–43.4)	38.7 (34.6–42.8)	39.5 (36.4–42.7)	40.4 (37.2–43.6)	41.3 (37.0–45.5)	42.1 (36.3–47.9)	43.1 (35.4–50.8)	
Frequent vomiting	5.3 (2.6–8.1)	5.9 (3.6–8.1)	6.4 (4.8–8.1)	7.0 (5.8–8.3)	7.7 (6.3–9.1)	8.4 (6.1–10.7)	9.2 (5.6–12.8)	

CHF = congestive heart failure.

* Analysis accounts for complex survey design.

† Adjusted prevalence was estimated from regression models of each symptom on time of death, with control for age at death, sex, race/ethnicity, number of nights spent in a hospital in the last 2 y of life, nursing home residency at the time of death and length of nursing home residency before death (regardless of site of death), number of activities of daily living dependencies (dressing, walking, bathing, eating, transferring, or toileting), diagnosis of arthritis (pain models only), depression reported in interview wave before death, highest education level, household wealth, annual household income, proxy's relationship to decedent, time elapsed between decedent's death and proxy's interview, average hours of care per week given to decedent from all informal caregivers, spouse's highest education level if proxy was spouse, English/Spanish preference for interview, and year that the decedent entered the Health and Retirement Study sample.

Appendix Table 3. Adjusted Estimated Prevalence of Symptoms Between 1998 and 2010 Among Decedent Categories, by Year of Death: Minimally Adjusted Models*

Outcome, by Category	Decedents (95% CI), %†						
	1998	2000	2002	2004	2006	2008	2010
Cancer							
Moderate or severe pain	58.4 (52.5–64.4)	59.5 (55.2–63.8)	60.6 (57.5–63.8)	61.7 (58.7–64.8)	62.8 (58.8–66.8)	63.9 (58.5–69.2)	65.0 (57.9–72.1)
Any pain	62.1 (56.3–67.9)	63.5 (59.3–67.7)	64.9 (61.9–67.9)	66.2 (63.6–68.8)	67.5 (64.3–70.8)	68.8 (64.4–73.3)	70.2 (64.3–76.1)
Depression	50.4 (45.7–55.1)	51.4 (47.8–54.9)	52.3 (49.5–55.2)	53.3 (50.4–56.2)	54.3 (50.6–57.9)	55.2 (50.3–60.1)	56.2 (49.9–62.5)
Periodic confusion	38.0 (33.3–42.8)	39.7 (36.1–43.2)	41.3 (38.6–44.0)	43.0 (40.4–45.6)	44.7 (41.3–48.0)	46.4 (41.8–51.0)	48.2 (42.1–54.4)
Dyspnea	52.6 (47.8–57.5)	53.0 (49.3–56.8)	53.5 (50.5–56.5)	53.9 (50.9–56.9)	54.3 (50.7–58.0)	54.8 (50.0–59.5)	55.2 (49.1–61.4)
Incontinence	44.3 (39.3–49.4)	43.6 (39.6–47.5)	42.9 (39.7–46.1)	42.1 (39.1–45.2)	41.4 (37.9–44.9)	40.7 (36.3–45.1)	39.9 (34.4–45.5)
Severe fatigue	77.0 (71.4–82.5)	77.4 (73.5–81.3)	77.8 (75.2–80.4)	78.3 (76.1–80.4)	78.7 (75.8–81.6)	79.1 (74.9–83.3)	79.6 (73.8–85.3)
Anorexia	77.0 (72.6–81.5)	78.2 (75.0–81.4)	79.3 (76.9–81.7)	80.3 (77.9–82.7)	81.3 (78.4–84.3)	82.3 (78.5–86.1)	83.3 (78.5–88.1)
Frequent vomiting	19.3 (14.4–24.3)	20.1 (16.2–24.0)	20.9 (17.9–23.9)	21.7 (19.2–24.3)	22.5 (19.8–25.3)	23.4 (19.7–27.0)	24.3 (19.3–29.4)
CHF or chronic lung disease							
Moderate or severe pain	49.4 (45.0–53.8)	50.7 (47.5–54.0)	52.0 (49.6–54.4)	53.3 (51.0–55.6)	54.6 (51.5–57.7)	55.9 (51.7–60.1)	57.3 (51.7–62.9)
Any pain	54.4 (50.5–58.4)	56.5 (53.5–59.5)	58.6 (56.2–60.9)	60.6 (58.2–63.0)	62.6 (59.6–65.6)	64.6 (60.7–68.4)	66.6 (61.8–71.5)
Depression	50.5 (45.4–55.6)	52.6 (48.7–56.6)	54.8 (51.7–57.8)	56.9 (54.3–59.4)	58.9 (56.2–61.7)	61.0 (57.6–64.4)	63.1 (58.7–67.6)
Periodic confusion	46.9 (41.7–52.1)	48.2 (44.3–52.1)	49.5 (46.6–52.4)	50.7 (48.4–53.1)	52.0 (49.4–54.6)	53.3 (49.8–56.8)	54.7 (49.9–59.4)
Dyspnea	74.3 (69.8–78.8)	74.6 (71.2–78.0)	74.9 (72.4–77.5)	75.2 (73.2–77.2)	75.5 (73.3–77.7)	75.8 (73.0–78.6)	76.1 (72.3–79.9)
Incontinence	48.4 (43.1–53.6)	48.6 (44.7–52.6)	48.9 (46.0–51.7)	49.1 (46.9–51.3)	49.3 (46.9–51.8)	49.6 (46.1–53.1)	49.8 (45.0–54.7)
Severe fatigue	68.2 (64.0–72.4)	68.3 (65.1–71.5)	68.4 (66.0–70.7)	68.4 (66.5–70.4)	68.5 (66.2–70.8)	68.6 (65.5–71.7)	68.7 (64.4–73.0)
Anorexia	68.5 (63.6–73.4)	68.7 (64.9–72.4)	68.8 (65.9–71.6)	68.9 (66.6–71.3)	69.1 (66.6–71.6)	69.2 (65.9–72.5)	69.3 (65.0–73.7)
Frequent vomiting	12.0 (8.2–15.7)	11.3 (8.7–14.0)	10.7 (8.9–12.5)	10.1 (8.8–11.4)	9.5 (8.0–11.1)	9.0 (7.0–11.1)	8.5 (5.8–11.2)
Frailty							
Moderate or severe pain	36.5 (29.9–43.1)	37.3 (32.3–42.3)	38.1 (34.4–41.8)	38.9 (35.7–42.0)	39.7 (35.9–43.5)	40.5 (35.3–45.7)	41.4 (34.3–48.5)
Any pain	42.7 (36.7–48.6)	43.9 (39.2–48.7)	45.2 (41.4–49.0)	46.5 (43.0–50.0)	47.8 (43.9–51.7)	49.1 (44.2–54.0)	50.5 (44.2–56.8)
Depression	42.6 (36.7–48.6)	45.3 (40.7–49.9)	47.9 (44.4–51.4)	50.6 (47.7–53.5)	53.2 (50.1–56.4)	55.9 (51.8–60.0)	58.7 (53.2–64.2)
Periodic confusion	69.3 (62.3–76.3)	72.0 (67.0–77.0)	74.5 (71.0–78.1)	76.9 (74.1–79.8)	79.2 (76.0–82.3)	81.2 (77.3–85.1)	83.3 (78.5–88.1)
Dyspnea	28.8 (22.4–35.2)	29.2 (24.3–34.1)	29.6 (26.1–33.2)	30.1 (27.4–32.8)	30.5 (27.6–33.4)	30.9 (27.0–34.9)	31.4 (25.8–37.1)
Incontinence	67.0 (59.9–74.0)	66.7 (61.1–72.4)	66.5 (62.0–71.0)	66.3 (62.5–70.2)	66.1 (62.1–70.1)	65.9 (61.0–70.8)	65.7 (59.4–72.0)
Severe fatigue	53.0 (46.4–59.7)	52.9 (48.1–57.6)	52.7 (49.4–56.0)	52.5 (49.4–55.5)	52.3 (48.1–56.4)	52.1 (46.1–58.0)	51.9 (43.8–60.0)
Anorexia	68.0 (59.9–76.1)	67.3 (61.2–73.5)	66.7 (62.2–71.1)	66.0 (62.5–69.5)	65.3 (61.5–69.2)	64.7 (59.2–70.1)	63.9 (56.3–71.6)
Frequent vomiting	6.7 (3.6–9.9)	6.5 (4.2–8.9)	6.4 (4.6–8.1)	6.2 (4.5–7.8)	6.0 (4.1–7.9)	5.8 (3.3–8.3)	5.6 (2.5–8.8)
Sudden death							
Moderate or severe pain	37.0 (29.6–44.3)	38.4 (32.9–43.9)	39.9 (36.0–43.7)	41.3 (38.4–44.3)	42.8 (39.3–46.3)	44.3 (39.2–49.4)	45.9 (38.7–53.2)
Any pain	43.8 (37.2–50.5)	46.2 (41.3–51.0)	48.5 (45.2–51.9)	50.9 (47.9–53.9)	53.3 (49.3–57.3)	55.6 (49.9–61.4)	58.2 (50.4–65.9)
Depression	38.3 (32.6–44.0)	39.8 (35.4–44.1)	41.2 (37.7–44.7)	42.7 (39.2–46.1)	44.1 (39.9–48.4)	45.6 (39.9–51.3)	47.2 (39.8–54.6)
Periodic confusion	25.7 (20.2–31.2)	27.6 (23.2–32.1)	29.6 (26.2–33.0)	31.7 (28.8–34.5)	33.8 (30.7–36.8)	36.0 (31.8–40.1)	38.4 (32.6–44.2)
Dyspnea	33.8 (28.6–39.1)	36.1 (31.8–40.4)	38.4 (34.8–42.0)	40.7 (37.4–44.1)	43.1 (39.4–46.9)	45.6 (40.9–50.2)	48.2 (42.2–54.2)
Incontinence	26.5 (19.7–33.3)	28.4 (23.0–33.8)	30.4 (26.4–34.5)	32.5 (29.4–35.6)	34.6 (31.4–37.8)	36.8 (32.4–41.3)	39.3 (32.9–45.6)
Severe fatigue	42.4 (36.5–48.3)	43.9 (39.6–48.2)	45.4 (42.3–48.4)	46.9 (44.1–49.6)	48.4 (44.6–52.1)	49.9 (44.5–55.2)	51.5 (44.2–58.7)
Anorexia	36.6 (31.3–41.9)	37.8 (33.8–41.8)	39.1 (35.8–42.3)	40.3 (36.8–43.9)	41.6 (36.9–46.3)	42.9 (36.6–49.2)	44.3 (36.1–52.6)
Frequent vomiting	4.9 (2.4–7.3)	5.5 (3.4–7.6)	6.2 (4.6–7.8)	7.0 (5.7–8.3)	7.8 (6.3–9.4)	8.8 (6.4–11.3)	10.0 (6.1–13.9)

CHF = congestive heart failure.

* Analysis accounts for complex survey design.

† Adjusted prevalence was estimated from regression models of each symptom on time of death, with control for age at death, sex, race/ethnicity, and time elapsed between decedent's death and proxy's interview.

Appendix Table 4. Adjusted Estimated Prevalence of Symptoms Between 1998 and 2010 Among Decedent Categories, by Year of Death: Fully Adjusted Models, Excluding 2002 Survey Wave*

Outcome, by Category	Decedents (95% CI), %†						
	1998	2000	2002	2004	2006	2008	2010
Entire population							
Moderate or severe pain	49.5 (46.1-52.9)	50.0 (47.4-52.6)	50.5 (48.5-52.5)	51.0 (49.3-52.6)	51.4 (49.8-53.1)	51.9 (49.8-54.1)	52.4 (49.6-55.3)
Any pain	55.3 (51.9-58.6)	56.2 (53.6-58.7)	57.1 (55.2-59.0)	58.0 (56.5-59.5)	58.9 (57.4-60.4)	59.8 (57.8-61.8)	60.8 (58.1-63.5)
Depression	45.5 (42.6-48.4)	47.3 (45.1-49.5)	49.1 (47.4-50.8)	50.9 (49.4-52.4)	52.7 (51.0-54.4)	54.5 (52.2-56.8)	56.4 (53.3-59.5)
Periodic confusion	42.0 (38.9-45.1)	43.9 (41.5-46.3)	45.8 (44.0-47.5)	47.7 (46.4-48.9)	49.6 (48.5-50.7)	51.5 (50.0-53.0)	53.5 (51.4-55.7)
Dyspnea	50.4 (47.9-52.8)	51.1 (49.2-52.9)	51.7 (50.3-53.2)	52.4 (51.2-53.6)	53.1 (51.7-54.5)	53.7 (51.9-55.6)	54.5 (52.0-56.9)
Incontinence	43.9 (40.5-47.4)	44.5 (41.9-47.1)	45.1 (43.2-47.0)	45.7 (44.3-47.1)	46.3 (44.9-47.7)	46.9 (45.0-48.9)	47.6 (44.8-50.4)
Severe fatigue	61.9 (59.2-64.7)	62.2 (60.1-64.2)	62.4 (61.0-63.9)	62.7 (61.5-63.9)	62.9 (61.5-64.4)	63.2 (61.2-65.2)	63.5 (60.7-66.2)
Anorexia	62.6 (59.5-65.7)	63.1 (60.8-65.4)	63.5 (61.9-65.2)	64.0 (62.6-65.4)	64.5 (62.8-66.1)	64.9 (62.7-67.1)	65.4 (62.3-68.4)
Frequent vomiting	12.6 (10.3-15.0)	12.4 (10.6-14.1)	12.1 (10.9-13.4)	11.9 (11.0-12.7)	11.6 (10.8-12.4)	11.4 (10.3-12.4)	11.1 (9.5-12.6)
Cancer							
Moderate or severe pain	59.8 (52.3-67.4)	60.5 (54.9-66.0)	61.1 (57.1-65.1)	61.7 (58.6-64.9)	62.4 (58.7-66.1)	63.0 (57.8-68.2)	63.7 (56.6-70.8)
Any pain	62.1 (54.9-69.3)	63.3 (58.0-68.6)	64.6 (60.9-68.2)	65.8 (63.0-68.5)	66.9 (63.8-70.0)	68.1 (63.8-72.4)	69.3 (63.3-75.3)
Depression	51.6 (46.1-57.0)	52.1 (48.0-56.2)	52.7 (49.5-55.8)	53.2 (50.2-56.2)	53.8 (50.0-57.6)	54.3 (49.3-59.4)	54.9 (48.3-61.6)
Periodic confusion	39.3 (33.9-44.6)	40.6 (36.5-44.6)	41.9 (38.8-44.9)	43.2 (40.5-45.9)	44.5 (41.2-47.8)	45.8 (41.3-50.3)	47.2 (41.1-53.3)
Dyspnea	50.5 (45.1-55.9)	51.3 (47.1-55.5)	52.0 (48.7-55.3)	52.7 (49.6-55.8)	53.5 (49.9-57.1)	54.2 (49.6-58.8)	55.0 (49.0-61.0)
Incontinence	42.2 (36.6-47.9)	42.0 (37.5-46.5)	41.8 (38.2-45.3)	41.5 (38.4-44.7)	41.3 (37.9-44.7)	41.1 (36.8-45.3)	40.8 (35.4-46.3)
Severe fatigue	75.3 (69.1-81.6)	76.3 (71.8-80.9)	77.3 (74.2-80.4)	78.2 (75.9-80.5)	79.1 (76.6-81.7)	80.0 (76.5-83.5)	80.9 (76.1-85.7)
Anorexia	77.1 (72.3-82.0)	78.2 (74.6-81.9)	79.3 (76.5-82.1)	80.3 (77.8-82.8)	81.3 (78.5-84.1)	82.3 (78.7-85.8)	83.2 (78.8-87.6)
Frequent vomiting	19.9 (13.5-26.2)	20.4 (15.3-25.5)	21.0 (17.1-24.9)	21.6 (18.6-24.6)	22.2 (19.3-25.0)	22.8 (19.2-26.3)	23.4 (18.5-28.4)
CHF or chronic lung disease							
Moderate or severe pain	53.1 (47.7-58.5)	53.3 (49.1-57.6)	53.5 (50.3-56.8)	53.8 (51.1-56.4)	54.0 (51.3-56.7)	54.2 (50.9-57.6)	54.5 (50.0-58.9)
Any pain	58.1 (53.1-63.0)	59.1 (55.2-62.9)	60.1 (57.1-63.0)	61.1 (58.6-63.5)	62.1 (59.5-64.6)	63.0 (59.9-66.1)	64.1 (60.0-68.1)
Depression	49.7 (44.2-55.3)	52.0 (47.7-56.3)	54.3 (51.0-57.5)	56.5 (54.0-59.1)	58.8 (56.1-61.4)	60.9 (57.7-64.2)	63.3 (58.9-67.6)
Periodic confusion	46.2 (40.1-52.3)	47.8 (43.2-52.5)	49.4 (46.1-52.8)	51.0 (48.7-53.4)	52.7 (50.4-54.9)	54.3 (51.2-57.3)	56.0 (51.6-60.4)
Dyspnea	75.2 (70.4-79.9)	75.2 (71.5-78.8)	75.2 (72.5-77.9)	75.2 (73.1-77.3)	75.2 (73.1-77.3)	75.2 (72.5-78.0)	75.2 (71.5-79.0)
Incontinence	50.0 (45.0-55.1)	50.1 (46.1-54.0)	50.1 (47.2-53.0)	50.1 (47.8-52.3)	50.1 (47.9-52.3)	50.1 (47.2-53.0)	50.1 (46.1-54.1)
Severe fatigue	69.3 (65.0-73.5)	69.0 (65.8-72.2)	68.7 (66.4-71.1)	68.5 (66.5-70.5)	68.2 (65.9-70.6)	68.0 (64.7-71.2)	67.7 (63.3-72.1)
Anorexia	69.4 (63.8-75.0)	69.4 (65.0-73.8)	69.3 (66.0-72.7)	69.3 (66.7-71.9)	69.3 (66.7-71.9)	69.2 (66.0-72.5)	69.2 (64.8-73.5)
Frequent vomiting	12.8 (8.4-17.2)	11.9 (8.8-15.0)	11.0 (9.0-13.1)	10.2 (8.8-11.7)	9.5 (8.0-11.0)	8.8 (6.8-10.8)	8.1 (5.5-10.7)
Frailty							
Moderate or severe pain	41.4 (33.4-49.4)	41.1 (35.1-47.2)	40.8 (36.5-45.1)	40.5 (37.4-43.6)	40.2 (37.0-43.5)	39.9 (35.4-44.5)	39.6 (33.1-46.1)
Any pain	49.4 (41.6-57.3)	49.2 (43.0-55.4)	49.0 (44.3-53.8)	48.8 (45.1-52.5)	48.6 (45.2-52.1)	48.4 (44.3-52.6)	48.2 (42.6-53.8)
Depression	44.6 (38.0-51.3)	46.8 (41.6-52.0)	49.0 (45.1-53.0)	51.2 (48.1-54.4)	53.4 (50.2-56.7)	55.6 (51.5-59.7)	58.0 (52.5-63.4)
Periodic confusion	72.3 (64.8-79.8)	74.2 (68.5-79.9)	76.0 (71.8-80.3)	77.8 (74.5-81.1)	79.5 (76.4-82.5)	81.0 (77.6-84.5)	82.6 (78.4-86.8)
Dyspnea	30.6 (23.6-37.6)	30.6 (25.3-35.9)	30.6 (26.9-34.3)	30.6 (28.0-33.2)	30.6 (28.1-33.2)	30.6 (27.0-34.3)	30.7 (25.3-36.0)
Incontinence	64.2 (57.2-71.2)	64.7 (59.3-70.0)	65.1 (61.1-69.2)	65.6 (62.4-68.8)	66.1 (62.9-69.3)	66.6 (62.4-70.7)	67.1 (61.5-72.6)
Severe fatigue	56.2 (48.4-63.9)	55.3 (49.5-61.1)	54.5 (50.3-58.7)	53.7 (50.3-57.1)	52.9 (48.9-56.8)	52.0 (46.5-57.6)	51.1 (43.5-58.8)
Anorexia	70.9 (61.9-79.8)	69.6 (62.7-76.4)	68.3 (63.5-73.1)	67.0 (63.6-70.3)	65.6 (62.0-69.1)	64.2 (58.8-69.6)	62.7 (54.6-70.8)
Frequent vomiting	7.1 (4.1-10.2)	6.8 (4.7-9.0)	6.5 (5.0-8.1)	6.3 (4.7-7.8)	6.0 (4.0-7.9)	5.7 (3.2-8.3)	5.5 (2.2-8.7)
Sudden death							
Moderate or severe pain	40.5 (33.0-48.1)	40.7 (35.0-46.4)	40.8 (36.7-44.8)	40.9 (38.0-43.8)	41.0 (38.1-43.9)	41.1 (37.0-45.2)	41.3 (35.4-47.2)
Any pain	49.0 (41.8-56.3)	49.7 (44.3-55.0)	50.3 (46.5-54.0)	50.9 (48.0-53.8)	51.6 (48.0-55.1)	52.2 (47.2-57.2)	52.9 (45.8-59.9)
Depression	38.7 (32.3-45.1)	39.8 (34.9-44.7)	40.9 (37.3-44.5)	42.0 (39.2-44.9)	43.1 (39.9-46.4)	44.3 (39.7-48.8)	45.5 (39.2-51.8)
Periodic confusion	26.4 (19.4-33.3)	28.1 (22.5-33.6)	29.8 (25.6-33.9)	31.5 (28.6-34.5)	33.4 (30.8-35.9)	35.2 (31.8-38.6)	37.2 (32.1-42.4)
Dyspnea	34.6 (29.0-40.2)	36.6 (32.2-41.1)	38.7 (35.2-42.2)	40.9 (37.8-43.9)	43.0 (39.6-46.4)	45.2 (40.8-49.6)	47.6 (41.7-53.5)
Incontinence	28.7 (23.8-33.6)	29.9 (23.7-36.1)	31.1 (26.6-35.6)	32.3 (29.1-35.6)	33.6 (30.6-36.6)	34.9 (30.8-39.0)	36.3 (30.2-42.3)
Severe fatigue	44.8 (37.7-51.9)	45.7 (40.4-51.0)	46.6 (43.0-50.3)	47.5 (44.9-50.2)	48.5 (45.5-51.5)	49.4 (44.9-53.9)	50.4 (44.0-56.8)
Anorexia	37.5 (30.9-44.1)	38.4 (33.5-43.3)	39.2 (35.6-42.9)	40.1 (36.8-43.5)	41.0 (36.7-45.3)	41.9 (36.0-47.8)	42.8 (34.9-50.8)
Frequent vomiting	6.4 (2.9-9.8)	6.7 (4.0-9.4)	7.0 (5.1-9.0)	7.4 (6.1-8.8)	7.8 (6.5-9.2)	8.2 (6.2-10.3)	8.7 (5.4-11.9)

CHF = congestive heart failure.

* Analysis accounts for complex survey design.

† Adjusted prevalence was estimated from regression models of each symptom on time of death, with control for age at death, sex, race/ethnicity, number of nights spent in a hospital in the last 2 y of life, nursing home residency at the time of death and length of nursing home residency before death (regardless of site of death), number of activities of daily living dependencies (dressing, walking, bathing, eating, transferring, or toileting), diagnosis of arthritis (pain models only), depression reported in interview wave before death, highest education level, household wealth, annual household income, proxy's relationship to decedent, time elapsed between decedent's death and proxy's interview, average hours of care per week given to decedent from all informal caregivers, spouse's highest education level if proxy was spouse, English/Spanish preference for interview, and year that the decedent entered the Health and Retirement Study sample.

Appendix Table 5. Adjusted Total Percentage of Change in Prevalence of Symptoms Between 1998 and 2010: Fully Adjusted Models, Excluding 2002 Survey Wave*

Outcome	Adjusted Change (95% CI), %†				
	Entire Population (n = 7204)	Cancer (n = 1546)	CHF or Chronic Lung Disease (n = 2293)	Frailty (n = 1175)	Sudden Death (n = 1161)
Moderate or severe pain	6.0 (−3.9 to 18.0)	6.5 (−10.3 to 28.1)	2.6 (−13.7 to 22.7)	−4.3 (−30.9 to 31.9)	1.8 (−23.4 to 40.2)
Any pain	10.0 (1.1 to 20.5)	11.6 (−4.6 to 32.0)	10.3 (−4.6 to 29.1)	−2.4 (−25.7 to 27.0)	7.8 (−15.1 to 39.1)
Depression	26.4 (13.7 to 40.5)	6.7 (−14.1 to 31.9)	30.1 (9.9 to 55.4)	31.5 (3.9 to 72.0)	20.7 (−9.5 to 61.8)
Periodic confusion	27.7 (15.0 to 41.6)	12.8 (−13.2 to 47.6)	21.0 (2.1 to 45.5)	13.7 (−0.5 to 31.4)	46.3 (4.2 to 113.4)
Dyspnea	9.8 (−0.4 to 21.3)	7.4 (−14.6 to 32.8)	0.6 (−9.1 to 12.7)	1.2 (−33.8 to 46.7)	35.9 (0.8 to 87.1)
Incontinence	9.5 (−1.9 to 21.2)	−6.9 (−29.6 to 22.2)	2.0 (−14.5 to 21.9)	4.5 (−14.1 to 26.2)	33.3 (−4.0 to 95.4)
Severe fatigue	2.9 (−5.2 to 11.5)	4.0 (−9.0 to 18.3)	−1.6 (−12.9 to 12.4)	−8.7 (−28.0 to 16.3)	13.0 (−13.3 to 49.4)
Anorexia	4.2 (−3.6 to 12.3)	7.2 (−4.1 to 20.1)	−0.2 (−12.2 to 13.5)	−12.4 (−27.6 to 5.7)	15.3 (−17.4 to 55.5)
Frequent vomiting	−10.1 (−33.1 to 21.7)	20.5 (−21.7 to 91.9)	−32.5 (−61.7 to 28.6)	−22.1 (−65.1 to 95.0)	41.0 (−39.8 to 226.9)

CHF = congestive heart failure.

* Analysis accounts for complex survey design.

† Adjusted percentage of change was estimated from regression models of each symptom on time of death, with control for age at death, sex, race/ethnicity, number of nights spent in a hospital in the last 2 y of life, nursing home residency at the time of death and length of nursing home residency before death (regardless of site of death), number of activities of daily living dependencies (dressing, walking, bathing, eating, transferring, or toileting), diagnosis of arthritis (pain models only), depression reported in interview wave before death, highest education level, household wealth, annual household income, proxy's relationship to decedent, time elapsed between decedent's death and proxy's interview, average hours of care per week given to decedent from all informal caregivers, spouse's highest education level if proxy was spouse, English/Spanish preference for interview, and year that the decedent entered the Health and Retirement Study sample. CIs are bootstrapped. 1029 decedents did not qualify for placement in any of the 4 categories.

Appendix Table 6. Adjusted Average Yearly Percentage of Change in Prevalence of Symptoms Between 1998 and 2010: Fully Adjusted Models*

Outcome	Adjusted Change (95% CI), %†				
	Entire Population (n = 7204)	Cancer (n = 1546)	CHF or Chronic Lung Disease (n = 2293)	Frailty (n = 1175)	Sudden Death (n = 1161)
Moderate or severe pain	1.4 (−0.4 to 3.2)	1.2 (−3.0 to 5.5)	0.7 (−2.2 to 3.8)	1.4 (−3.5 to 6.5)	−0.4 (−4.7 to 4.2)
Any pain	2.4 (0.6 to 4.1)	2.0 (−2.2 to 6.3)	2.5 (−0.2 to 5.3)	2.4 (−1.5 to 6.3)	1.6 (−3.0 to 6.4)
Depression	3.8 (2.0 to 5.7)	1.4 (−2.1 to 4.9)	4.3 (1.3 to 7.4)	5.7 (1.8 to 9.8)	2.1 (−2.1 to 6.5)
Periodic confusion	5.4 (3.6 to 7.2)	3.6 (−0.2 to 7.5)	4.7 (1.7 to 7.8)	7.8 (2.6 to 13.2)	5.8 (0.6 to 11.4)
Dyspnea	1.3 (−0.1 to 2.7)	0.3 (−2.8 to 3.5)	0.2 (−3.1 to 3.6)	1.1 (−3.1 to 5.5)	5.0 (1.6 to 8.6)
Incontinence	2.0 (−0.2 to 4.2)	−0.8 (−3.8 to 2.4)	1.5 (−1.5 to 4.6)	1.1 (−2.9 to 5.1)	3.4 (−2.5 to 9.7)
Severe fatigue	1.2 (−0.7 to 3.2)	3.0 (−2.1 to 8.3)	−0.8 (−4.0 to 2.5)	−0.1 (−4.1 to 4.1)	2.9 (−1.6 to 7.5)
Anorexia	1.3 (−0.8 to 3.4)	3.0 (−1.3 to 7.5)	0.3 (−3.0 to 3.7)	−1.5 (−7.1 to 4.4)	2.0 (−2.8 to 7.0)
Frequent vomiting	−1.1 (−3.6 to 1.4)	0.8 (−3.7 to 5.6)	−3.9 (−8.6 to 1.1)	−3.0 (−12.0 to 6.9)	5.4 (−2.7 to 14.2)

CHF = congestive heart failure.

* Analysis accounts for complex survey design.

† Adjusted percentage of change was estimated from regression models of each symptom on survey year, with control for age at death, sex, race/ethnicity, number of nights spent in a hospital in the last 2 y of life, nursing home residency at the time of death and length of nursing home residency before death (regardless of site of death), number of activities of daily living dependencies (dressing, walking, bathing, eating, transferring, or toileting), diagnosis of arthritis (pain models only), depression reported in interview wave before death, highest education level, household wealth, annual household income, proxy's relationship to decedent, time elapsed between decedent's death and proxy's interview, average hours of care per week given to decedent from all informal caregivers, spouse's highest education level if proxy was spouse, English/Spanish preference for interview, and year that the decedent entered the Health and Retirement Study sample. 1029 decedents did not qualify for placement in any of the 4 categories.