Symptom trends in the last year of life, 1998-2010: A cohort study

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Abstract

Background—Research in the 1990s described serious symptoms at the end of life, and a 1997 Institute of Medicine report called for improvement. Hospice and palliative care have grown considerably since then.

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

Design—Observational study.

Setting—Health and Retirement Study (HRS), a nationally representative longitudinal survey of community-dwelling US residents aged 51 and older.

Participants—7,204 HRS participants who died while enrolled in the study, and their family respondents.

Measurements—Proxy-reported pain during the last year of life; depression, confusion, dyspnea, incontinence, fatigue, anorexia, and vomiting for a period of at least one month during the last year of life. Trends in pain intensity and symptom prevalence were analyzed among all

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decedents and those within cancer, congestive heart failure or chronic lung disease, frailty, and sudden death.

Results—Between 1998 and 2010, proxy reports of the prevalence of any pain (mild, moderate, or severe) increased for all decedents by 11.9% (95% CI: 3.1%, 21.4%). Reported prevalence of depression increased for all decedents by 26.6% (14.5%, 40.1%), for congestive heart failure or chronic lung disease by 27.0% (8.1%, 49.3%), and for frailty by 39.4% (9.9%, 79.8%). Reported prevalence of periodic confusion increased for all decedents by 31.3% (18.6%, 45.1%), for congestive heart failure or chronic lung disease by 24.9% (6.0%, 47.6%), for frailty by 20.3% (5.9%, 39.1%), and for sudden death by 45.7% (5.9%, 106.1%). Trends in the reported prevalence of most other symptoms in most groups of decedents were positive but not significant. Moderate or severe pain, severe fatigue, anorexia, and frequent vomiting did not show significant changes in any group of decedents. There were no significant changes for cancer.

Limitation—Proxy reports, mostly yes/no symptom questions.

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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Introduction

In a seminal 1997 report on the state of end-of-life care, the Institute of Medicine (IOM) 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 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 have lacked definitive population-based data, systematic reviews show the high prevalence of many symptoms, including pain, dyspnea, and depression, across multiple advanced diseases.[12] Pain is among the most prevalent and troubling of symptoms, and patients and families fear 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 IOM 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 population as a whole 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 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 Health and Retirement Study (HRS), a nationally representative longitudinal survey of community-dwelling adults aged 51 or older in the contiguous United States.[16,17] The mortality rate of the HRS population is comparable to that of the overall United States population of adults aged 51 and older. HRS participants are interviewed every two years until their deaths. After each participant's death, HRS interviews a proxy informant, typically a family member, who was most familiar with the health, family, and financial situation of the participant. We included participants who died while enrolled in HRS and whose proxy informant provided a postmortem interview within two years of death.

Symptom Outcomes

We evaluated symptom prevalence using eight yes/no questions that asked about the presence of pain, depression, periodic confusion, dyspnea, severe fatigue, incontinence, anorexia, and frequent vomiting. All symptom questions excluding pain asked if the decedent experienced the symptom for a period of at least one month during the last year of life; for pain only, the question asked if the decedent were often troubled with pain in the last year of life. In addition, a follow-up question asked about the degree of pain (mild, moderate, or severe) if pain were present. We analyzed any pain and moderate or severe pain separately. Appendix Table 1 provides the exact wording for all symptom questions.

Symptom Covariates

We employed a model of whole person distress, which included demographics as well as clinical, psychological, and social domains, and which we modified to include proxy factors. Demographics included age at death, gender, and race/ethnicity. Clinical covariates included number of nights spent in a hospital in the last two years of life, nursing home residency at the time of death and length of nursing home residency prior to death (regardless of site of death), number of ADL dependencies (0-6 scale comprised of help with 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 prior to death, as indicated by a score of four or more on an eight-item subset of the 20-item Center for Epidemiologic Studies Depression Scale.[18,19] The social covariates included highest level of education, household wealth, and household income. Proxy covariates included relationship of proxy to decedent (spouse, son or daughter, or other); time elapsed between decedent's death and proxy's interview; average hours per week of care given to decedent from all informal carers, including care given by proxy; highest level of education (only available if proxy was spouse [approximately 33% of proxies]); and English/Spanish preference for interview. In addition, we also included the year that the decedent entered the HRS sample.

Decedent Categories

We employed a sequential categorization scheme based on prior work to resolve decedents into four mutually exclusive categories: sudden death, cancer, congestive heart failure (CHF) or chronic lung disease, and frailty.[20-23] Decedents were categorized as (1) sudden death, if they died within one day of receiving their terminal diagnosis; (2) cancer, if their proxy reported cancer as their cause of death; (3) CHF or chronic lung disease, if they or their proxy reported a diagnosis of either or both of these conditions; or (4) 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 two years of life.

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

Statistical Analysis

All analyses accounted for complex survey design using sampling weights, providing estimates representative of the entire US population. We used multivariable logistic regression models to investigate the association between each symptom outcome and time of death. We employed two sets of models for each outcome: a fully adjusted model that included all symptom covariates described above, and a minimally adjusted model that included only demographics and time elapsed between decedent's death and proxy's interview. We conducted all analyses for the cohort as a whole and in each of the four mutually exclusive decedent categories. All decedents were included in the entire population analysis, and decedents who qualified for membership in one of the four categories were also analyzed separately in that category.

We report adjusted prevalence of each symptom by year of death from both fully and minimally adjusted models. We estimated the percent change in the adjusted prevalence of each symptom using first and last death dates from all regressions, and used bootstrapping with bias correction to estimate confidence intervals.[24] We report adjusted percent change in the prevalence of each symptom from both fully and minimally adjusted models.

We imputed missing values using multiple imputation by chained equations with 15 imputed datasets using Stata's "ice" command;[25] analyses in imputed data were carried out with "mi estimate" commands or manually using Rubin's rules.[26] We constructed a multiple imputation model that included time of death, decedent categories, all symptom outcome variables, and all symptom covariates described above except for the year that the decedent entered the HRS sample. Two sets of variables were imputed using forms different from those included in regression analyses: (1) pain was captured with one 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; (2) the six ADL questions were included separately in the imputation model and combined into a scale after imputation.

Of the 31 total variables in the imputation model, 12 had no missing values and were not themselves imputed. The remaining 19 variables were imputed (numbers of missing values are presented here): pain categorical variable (241), depression (225), periodic confusion (53), dyspnea (54), incontinence (128), severe fatigue (123), anorexia (212), frequent vomiting (99), race/ethnicity (7), number of nights spent in a hospital in the last two years of life (582), help with dressing (31), help with walking (26), help with bathing (31), help with eating (33), help with transferring (43), help with toileting (44), diagnosis of arthritis (4), depression in interview wave prior to death (485), and household wealth (75).

In the 2002 survey wave only, approximately 41% of proxies were erroneously not asked non-pain symptom questions due to faulty survey logic. Upon discovering the issue, HRS corrected the survey logic but did not go back and collect the missing data. As a result, those responses were permanently lost. In our main analyses, we excluded those 41% of proxies in the 2002 survey wave only. As a sensitivity analysis, we also replicated these analyses excluding the entire 2002 survey wave to investigate the effect of potentially non-random 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 average yearly percent change and confidence intervals.

We conducted analyses with Stata 12.1 IC (StataCorp, College Station, Texas). The RAND IRB approved the study.

Role of the Funding Source

Results

8,641 HRS participants died between 1998 and 2010, for which 8,089 proxy interviews were completed. Of those, 7,204 proxy interviews were completed within two years of the decedent's death. The latter comprised our study cohort. The response rates for the six 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 timing of death. Their mean age at death was 79.1 years. Fifty-four percent were women; 17% were nonwhite. Twenty-two percent were reported to have had cancer; 33%, CHF or chronic lung disease; 16%, frailty; and 16%, sudden death. 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 both fully and minimally adjusted models for all decedents between 1998 and 2010; Appendix Tables 2 and 3 present this information for cancer, CHF or chronic lung disease, frailty, and sudden death. These estimates are largely similar between the two sets of models and show the high prevalence of most symptoms in the entire population and in all decedent categories. Most estimates also suggest positive trends in prevalence over time.

Table 3 presents the adjusted percent change in prevalence of symptoms from both fully and minimally adjusted models among all decedents and for cancer, CHF or chronic lung disease, frailty, and sudden death. In 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%, 21.4%) between 1998 and 2010. Reported prevalences of depression and periodic confusion each increased for all decedents and in multiple decedent categories by large percentages (between 20.3% and 45.7%). Incontinence also increased for all decedents, and dyspnea increased for sudden death. Trends in the reported prevalence of most other symptoms in most groups of decedents were positive but not significant. Moderate or severe pain, severe fatigue, anorexia, and frequent vomiting did not show significant changes in any group of decedents. There were no significant changes for cancer.

As compared with fully adjusted models, minimally adjusted models generally showed larger trends, and more trends were significant. Proxy reports of moderate or severe pain increased for all decedents by 20.9% (95% CI: 9.7%, 32.9%), and reports of any pain increased for all decedents by 23.3% (13.4%, 33.9%), for CHF or chronic lung disease by 22.5% (7.0%, 41.7%), and for sudden death by 32.8% (5.3%, 68.9%). Increases in the reported prevalences of depression and periodic confusion for all decedents and in multiple decedent categories were similar to those in fully adjusted models. Dyspnea, severe fatigue, and anorexia also increased for all decedents, and dyspnea and incontinence increased for sudden death. As with fully adjusted models, there were no significant changes for cancer.

We performed two sensitivity analyses for fully adjusted models: estimating symptom prevalence and percent change excluding the 2002 survey wave (Appendix Tables 4 and 5), and investigating yearly changes rather than 12-year changes (Appendix Table 6). Overall results do not differ appreciably between analyses with and without the 2002 survey wave, and the magnitude and significance of yearly changes generally comport with those of 12-year changes.

Discussion

We analyzed bereaved family interviews conducted on behalf of decedents in a large, nationally representative survey in order 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 in 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 there remain persistent gaps in addressing symptoms near the end of life.[27-29] It is particularly concerning that proxy reports of pain have increased, as pain is among the most visible and well-studied aspect of the end-of-life experience, has received policy attention, and significantly impacts health-related quality of life (HRQOL).[6] Moderate and severe pain, for example, has an HRQOL impact more pronounced than many health and sociodemographic factors.[30,31] It is encouraging, however, that trends in cancer pain prevalence and severity may have stabilized. This should be monitored in the face of growing public concern about prescription opioid abuse, which may create resistance to using opioids from both 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 population-level studies available from other countries. Cancer outpatients in Canada assessed between diagnosis and death reported the prevalence of pain, dyspnea, depression, and anorexia between 45% and 60%, and fatigue at 75%.[33] Dyspnea prevalence among hospice patients in Australia at three months prior to death was 50% overall, 65% for heart failure, and 88% for end-stage pulmonary disease.[34]

There are many factors that could contribute to the persistence and potential increase in prevalence of these troubling end-of-life symptoms. Recent reports demonstrate 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: even though hospice use doubled from 2000 to 2009, the median stay is less than three weeks.[7,35] Some patients who have short stays may not realize the full benefits of hospice for symptomatic relief. Palliative care services remain 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 (e.g., opioid regimens for pain and dyspnea),[36] but there remain significant gaps in their delivery near the end of life.[37,38] This suggests that interventions may not be reaching the right patients in the right ways.

In addition, increased attention to end-of-life care generally 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 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 impact of a variety of 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] but is unlikely to explain symptom trends, since proxies were used in all survey waves. 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 non-pain outcomes, the increase in their prevalence raises concerns. Third, due to 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 as 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 due to 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 simply to benchmark current practice against current knowledge. Future research should evaluate settings that provide better and worse end-of-life symptom management in order 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.

Acknowledgments

Appendix

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 one month during the last year of [his/her] life when [he/she] had the following problems: difficulty breathing?
Anorexia	C199	Was there a period of at least one 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 one month during the last year of [his/her] life when [he/she] had frequent vomiting?
Depression	C202	Was there a period of at least one month during the last year of [his/her] life when [he/she] had depression?
Periodic confusion	C203	Was there a period of at least one month during the last year of [his/her] life when [he/she] had periodic confusion?

Outcome	HRS Variable	Question to Proxy
Severe fatigue	C204	Was there a period of at least one 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 one month during the last year of [his/her] life when [he/she] had loss of control of bowel or bladder?

Appendix Table 2

Adjusted Estimated Prevalence of Symptoms between 1998 and 2010 among Decedent Categories (Fully Adjusted Models)[a]

Category	Outcome	% of Decedents (95% CIs)[b]						
		Year of Death						
		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)

		% of Decedents (95% CIs)[b]						
		Year of Death						
Category	**Outcome**	**1998**	**2000**	**2002**	**2004**	**2006**	**2008**	**2010**
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)

[a] Analysis accounts for complex survey design

[b] Adjusted prevalence is predicted from regression models of each symptom on time of death, controlling for age at death, gender, race/ethnicity, number of nights spent in a hospital in the last two years of life, nursing home residency at the time of death and length of nursing home residency prior to death (regardless of site of death), number of ADL dependencies (0-6 scale), diagnosis of arthritis (pain models only), depression reported in interview wave prior to death, highest level of education, household wealth, household income, proxy relationship to decedent, time elapsed between decedent's death and proxy's interview, average hours per week of care given to decedent from all informal carers, highest level of education if proxy was spouse, English/Spanish preference for interview, and year that the decedent entered the HRS sample

Appendix Table 3

Adjusted Estimated Prevalence of Symptoms between 1998 and 2010 among Decedent Categories (Minimally Adjusted Models)[a]

Category	Outcome	% of Decedents (95% CIs)[b]						
		Year of Death						
		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)

		% of Decedents (95% CIs)[b]						
		Year of Death						
Category	Outcome	1998	2000	2002	2004	2006	2008	2010
	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)

[a] Analysis accounts for complex survey design

[b] Adjusted prevalence is predicted from regression models of each symptom on time of death, controlling for age at death, gender, 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 (Fully Adjusted Models Excluding 2002 Survey Wave)[a]

		% of Decedents (95% CIs)[b]						
		Year of Death						
Category	Outcome	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)

| Category | Outcome | % of Decedents (95% CIs)[b] | | | | | | |
| | | Year of Death | | | | | | |
		1998	2000	2002	2004	2006	2008	2010
	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)

Category	Outcome	% of Decedents (95% CIs)[b]						
		Year of Death						
		1998	2000	2002	2004	2006	2008	2010
	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 (20.8, 36.6)	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)

[a] Analysis accounts for complex survey design

[b] Adjusted prevalence is predicted from regression models of each symptom on time of death, controlling for age at death, gender, race/ethnicity, number of nights spent in a hospital in the last two years of life, nursing home residency at the time of death and length of nursing home residency prior to death (regardless of site of death), number of ADL dependencies (0-6 scale), diagnosis of arthritis (pain models only), depression reported in interview wave prior to death, highest level of education, household wealth, household income, proxy relationship to decedent, time elapsed between decedent's death and proxy's interview, average hours per week of care given to decedent from all informal carers, highest level of education if proxy was spouse, English/Spanish preference for interview, and year that the decedent entered the HRS sample

Appendix Table 5

Adjusted Total Percent Change in Prevalence of Symptoms between 1998 and 2010 (Fully Adjusted Models Excluding 2002 Survey Wave)[a]

Outcome	Adjusted % Change (95% CIs)[b]				
	Entire Population (n = 7,204)	Cancer (n = 1,546)	CHF or Chronic Lung Disease (n = 2,293)	Frailty (n = 1,175)	Sudden Death (n = 1,161)
Moderate or severe pain	6.0 (-3.9, 18.0)	6.5 (-10.3, 28.1)	2.6 (-13.7, 22.7)	-4.3 (-30.9, 31.9)	1.8 (-23.4, 40.2)
Any pain	10.0 (1.1, 20.5)	11.6 (-4.6, 32.0)	10.3 (-4.6, 29.1)	-2.4 (-25.7, 27.0)	7.8 (-15.1, 39.1)
Depression	26.4 (13.7, 40.5)	6.7 (-14.1, 31.9)	30.1 (9.9, 55.4)	31.5 (3.9, 72.0)	20.7 (-9.5, 61.8)
Periodic confusion	27.7 (15.0, 41.6)	12.8 (-13.2, 47.6)	21.0 (2.1, 45.5)	13.7 (-0.5, 31.4)	46.3 (4.2, 113.4)
Dyspnea	9.8 (-0.4, 21.3)	7.4 (-14.6, 32.8)	0.6 (-9.1, 12.7)	1.2 (-33.8, 46.7)	35.9 (0.8, 87.1)
Incontinence	9.5 (-1.9, 21.2)	-6.9 (-29.6, 22.2)	2.0 (-14.5, 21.9)	4.5 (-14.1, 26.2)	33.3 (-4.0, 95.4)
Severe fatigue	2.9 (-5.2, 11.5)	4.0 (-9.0, 18.3)	-1.6 (-12.9, 12.4)	-8.7 (-28.0, 16.3)	13.0 (-13.3, 49.4)
Anorexia	4.2 (-3.6, 12.3)	7.2 (-4.1, 20.1)	-0.2 (-12.2, 13.5)	-12.4 (-27.6, 5.7)	15.3 (-17.4, 55.5)
Frequent vomiting	-10.1 (-33.1, 21.7)	20.5 (-21.7, 91.9)	-32.5 (-61.7, 28.6)	-22.1 (-65.1, 95.0)	41.0 (-39.8, 226.9)

[a] Analysis accounts for complex survey design

[b] Percent change is predicted from fully adjusted regression models of each symptom on date of death; confidence intervals are bootstrapped

Appendix Table 6

Adjusted Average Yearly Percent Change in Prevalence of Symptoms between 1998 and 2010 (Fully Adjusted Models)[a]

Outcome	Adjusted % Change (95% CIs)[b]				
	Entire Population (n = 7,204)	Cancer (n = 1,546)	CHF or Chronic Lung Disease (n = 2,293)	Frailty (n = 1,175)	Sudden Death (n = 1,161)
Moderate or severe pain	1.4 (-0.4, 3.2)	1.2 (-3.0, 5.5)	0.7 (-2.2, 3.8)	1.4 (-3.5, 6.5)	-0.4 (-4.7, 4.2)
Any pain	2.4 (0.6, 4.1)	2.0 (-2.2, 6.3)	2.5 (-0.2, 5.3)	2.4 (-1.5, 6.3)	1.6 (-3.0, 6.4)
Depression	3.8 (2.0, 5.7)	1.4 (-2.1, 4.9)	4.3 (1.3, 7.4)	5.7 (1.8, 9.8)	2.1 (-2.1, 6.5)
Periodic confusion	5.4 (3.6, 7.2)	3.6 (-0.2, 7.5)	4.7 (1.7, 7.8)	7.8 (2.6, 13.2)	5.8 (0.6, 11.4)
Dyspnea	1.3 (-0.1, 2.7)	0.3 (-2.8, 3.5)	0.2 (-3.1, 3.6)	1.1 (-3.1, 5.5)	5.0 (1.6, 8.6)
Incontinence	2.0 (-0.2, 4.2)	-0.8 (-3.8, 2.4)	1.5 (-1.5, 4.6)	1.1 (-2.9, 5.1)	3.4 (-2.5, 9.7)
Severe fatigue	1.2 (-0.7, 3.2)	3.0 (-2.1, 8.3)	-0.8 (-4.0, 2.5)	-0.1 (-4.1, 4.1)	2.9 (-1.6, 7.5)
Anorexia	1.3 (-0.8, 3.4)	3.0 (-1.3, 7.5)	0.3 (-3.0, 3.7)	-1.5 (-7.1, 4.4)	2.0 (-2.8, 7.0)

Outcome	Adjusted % Change (95% CIs)[b]				
	Entire Population (n = 7,204)	Cancer (n = 1,546)	CHF or Chronic Lung Disease (n = 2,293)	Frailty (n = 1,175)	Sudden Death (n = 1,161)
Frequent vomiting	-1.1 (-3.6, 1.4)	0.8 (-3.7, 5.6)	-3.9 (-8.6, 1.1)	-3.0 (-12.0, 6.9)	5.4 (-2.7, 14.2)

[a] Analysis accounts for complex survey design

[b] Adjusted percent change is predicted from regression models of each symptom on survey year, controlling for age at death, gender, race/ethnicity, number of nights spent in a hospital in the last two years of life, nursing home residency at the time of death and length of nursing home residency prior to death (regardless of site of death), number of ADL dependencies (0-6 scale), diagnosis of arthritis (pain models only), depression reported in interview wave prior to death, highest level of education, household wealth, household income, proxy relationship to decedent, time elapsed between decedent's death and proxy's interview, average hours per week of care given to decedent from all informal carers, highest level of education if proxy was spouse, English/Spanish preference for interview, and year that the decedent entered the HRS sample

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Table 1

Characteristics of Study Population[a]

Characteristic	All (n = 7,204)	% of Decedents[b] Interval of Death					
		1998-2000 (n = 1,243)	2000-2002 (n = 1,226)	2002-2004 (n = 1,144)	2004-2006 (n = 1,186)	2006-2008 (n = 1,212)	2008-2010 (n = 1,193)
Age at death							
< 65	12.3	13.7	10.4	7.8	14.6	14.6	12.0
65-74	19.6	20.4	21.2	18.1	18.3	18.5	21.3
75-84	32.6	33.0	33.2	39.1	31.5	30.4	29.2
> 84	35.5	32.9	35.2	35.0	35.6	36.5	37.5
Women	53.6	51.3	53.0	54.4	51.4	55.9	55.4
Ethnicity							
Non-Hispanic White	83.2	84.4	82.3	83.7	81.9	83.1	83.8
Non-Hispanic Black	10.3	10.3	10.7	9.9	10.6	10.6	9.9
Hispanic	4.6	3.7	4.9	4.4	4.9	4.7	4.9
Other	1.9	1.6	2.1	2.0	2.7	1.6	1.4
Decedent categories							
Cancer	22.2	23.8	21.8	21.2	20.9	22.5	22.9
CHF or chronic lung disease	32.5	27.7	30.9	32.9	34.8	33.5	34.6
Frailty	15.5	14.5	15.0	15.4	16.1	16.9	14.8
Sudden death	15.7	18.7	14.9	15.7	13.4	16.1	15.7
Symptoms							
Moderate or severe pain	50.6	46.7	47.7	49.9	51.9	51.5	54.8
Any pain	57.5	53.1	53.9	56.8	58.7	57.9	63.6
Depression	51.4	44.6	49.5	51.8	52.0	53.2	55.5
Periodic confusion	47.9	41.7	42.8	46.1	49.6	54.1	49.1
Dyspnea	52.6	49.8	51.9	52.4	50.9	53.5	56.2
Incontinence	45.8	41.9	43.2	47.6	47.1	46.3	46.8
Severe fatigue	62.4	59.2	57.9	63.0	66.6	62.7	62.6

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Characteristic	All (n = 7,204)	1998-2000 (n = 1,243)	2000-2002 (n = 1,226)	2002-2004 (n = 1,144)	2004-2006 (n = 1,186)	2006-2008 (n = 1,212)	2008-2010 (n = 1,193)
				% of Decedents[b] Interval of Death			
Anorexia	64.0	62.1	61.1	62.1	65.0	67.6	64.1
Frequent vomiting	11.8	11.4	11.4	11.5	11.4	13.5	11.1
Comorbid conditions							
Depression	26.4	25.9	27.8	27.1	25.7	26.1	26.0
Arthritis	67.6	57.8	65.3	70.5	69.0	70.4	71.2
2+ ADLs (0-6 scale)	70.6	66.8	67.8	70.5	73.6	71.2	72.7
Health care utilization							
Median hospital nights in last two years of life (IQR)	7 (0-20)	5 (0-19)	7 (0-21)	6 (0-20)	7 (0-21)	7 (0-20)	7 (0-20)
Nursing home residency at time of death	28.0	28.8	29.9	29.2	26.9	29.2	24.2
Median hours of informal care received per week in last two years of life (IQR)	15 (0-93)	13 (0-75)	16 (0-90)	14 (0-88)	18 (0-106)	14 (0-111)	21 (1-103)
Highest level of education							
Some high school or less	55.4	60.2	60.3	54.1	54.2	52.3	52.5
High school graduate	29.4	27.8	26.2	30.2	30.3	30.4	30.8
Some college or more	15.2	12.1	13.5	15.8	15.5	17.2	16.7
Median household wealth (IQR), $	83,000 (8,000-273,000)	72,000 (7,000-209,000)	81,000 (8,000-220,000)	94,000 (8,000-259,000)	89,000 (3,000-265,000)	83,000 (6,000-330,000)	102,000 (8,000-336,000)
Median income (IQR), $	20,000 (11,000-36,000)	17,000 (10,000-32,000)	18,000 (10,000-34,000)	18,000 (11,000-32,000)	21,000 (12,000-39,000)	21,000 (12,000-38,000)	24,000 (13,000-45,000)
Relationship of proxy to decedent							
Spouse	32.9	34.0	33.7	30.3	36.2	31.8	31.3
Son or daughter	44.8	42.9	41.9	44.0	43.7	46.5	49.0
Other	22.3	23.1	24.4	25.8	20.1	21.7	19.6
Mean months between decedent's death and proxy's interview (95% CI)	11.3 (11.1-11.5)	11.5 (11.1-11.9)	12.6 (12.1-13.0)	11.0 (10.5-11.5)	10.9 (10.4-11.3)	10.7 (10.2-11.1)	11.5 (11.1-11.9)
Highest spouse level of education (if spouse was proxy)							
Some high school or less	43.4	42.4	45.4	44.5	42.2	45.3	41.0
High school graduate	37.1	41.0	36.7	39.7	38.7	33.3	33.5

Characteristic	All (n = 7,204)	% of Decedents[b] Interval of Death						
		1998-2000 (n = 1,243)	2000-2002 (n = 1,226)	2002-2004 (n = 1,144)	2004-2006 (n = 1,186)	2006-2008 (n = 1,212)	2008-2010 (n = 1,193)
Some college or more	19.5	16.6	17.9	15.8	19.1	21.4	25.4
Interview conducted in English	98.3	98.4	98.2	98.4	98.2	98.3	98.1

[a]Reported values account for complex survey design

[b]Percentages are rounded and may not sum to 100%

Table 2

Adjusted Estimated Prevalence of Symptoms between 1998 and 2010 in the Entire Population[a]

	% of Decedents (95% CIs)						
	Year of Death						
	Models adjusted for demographics and clinical, psychological, social, and proxy characteristics[b]						
Outcome	**1998**	**2000**	**2002**	**2004**	**2006**	**2008**	**2010**
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[c]						
Outcome	**1998**	**2000**	**2002**	**2004**	**2006**	**2008**	**2010**
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)

	% of Decedents (95% CIs)						
	Year of Death						
	Models adjusted for demographics and clinical, psychological, social, and proxy characteristics[b]						
Outcome	**1998**	**2000**	**2002**	**2004**	**2006**	**2008**	**2010**
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)

[a] Analysis accounts for complex survey design

[b] Adjusted prevalence is predicted from regression models of each symptom on time of death, controlling for age at death, gender, race/ethnicity, number of nights spent in a hospital in the last two years of life, nursing home residency at the time of death and length of nursing home residency prior to death (regardless of site of death), number of ADL dependencies (0-6 scale), diagnosis of arthritis (pain models only), depression reported in interview wave prior to death, highest level of education, household income, household wealth, proxy relationship to decedent, time elapsed between decedent's death and proxy's interview, average hours per week of care given to decedent from all informal carers, highest level of education if proxy was spouse, English/Spanish preference for interview, and year that the decedent entered the HRS sample

[c] Adjusted prevalence is predicted from regression models of each symptom on time of death, controlling for age at death, gender, race/ethnicity, and time elapsed between decedent's death and proxy's interview

Table 3

Adjusted Total Percent Change in Prevalence of Symptoms between 1998 and 2010[a]

	Adjusted % Change (95% CIs)				
	Models adjusted for demographics and clinical, psychological, social, and proxy characteristics[b]				
Outcome	Entire Population (n = 7,204)	Cancer (n = 1,546)	CHF or Chronic Lung Disease (n = 2,293)	Frailty (n = 1,175)	Sudden Death (n = 1,161)
Moderate or severe pain	7.6 (-1.9, 18.4)	4.8 (-10.9, 24.0)	4.2 (-10.6, 23.3)	6.8 (-21.8, 43.9)	-3.0 (-26.2, 28.5)
Any pain	11.9 (3.1, 21.4)	7.9 (-6.7, 25.5)	12.0 (-2.0, 29.0)	12.4 (-13.3, 45.5)	8.0 (-13.9, 35.7)
Depression	26.6 (14.5, 40.1)	8.8 (-11.6, 33.4)	27.0 (8.1, 49.3)	39.4 (9.9, 79.8)	17.0 (-10.4, 53.0)
Periodic confusion	31.3 (18.6, 45.1)	26.3 (-1.6, 61.1)	24.9 (6.0, 47.6)	20.3 (5.9, 39.1)	45.7 (5.9, 106.1)
Dyspnea	9.2 (-1.0, 19.9)	4.4 (-15.8, 27.0)	0.5 (-8.7, 11.8)	8.9 (-28.1, 56.2)	36.7 (2.3, 85.9)
Incontinence	11.9 (1.0, 23.6)	-4.4 (-26.1, 21.7)	10.0 (-7.2, 30.5)	2.8 (-14.1, 21.7)	29.3 (-5.1, 82.4)
Severe fatigue	4.9 (-2.9, 13.7)	7.0 (-5.5, 21.4)	-2.3 (-13.2, 10.6)	-1.8 (-22.1, 25.4)	16.4 (-10.5, 51.7)
Anorexia	5.1 (-2.4, 13.2)	7.4 (-3.7, 18.8)	0.8 (-10.6, 13.7)	-7.5 (-23.2, 10.4)	13.9 (-16.4, 50.3)
Frequent vomiting	-8.8 (-31.2, 21.5)	11.4 (-26.0, 72.8)	-30.5 (-60.2, 26.8)	-26.4 (-66.0, 69.4)	72.5 (-30.4, 305.7)
	Minimally adjusted models[c]				
Outcome	Entire Population (n = 7,204)	Cancer (n = 1,546)	CHF or Chronic Lung Disease (n = 2,293)	Frailty (n = 1,175)	Sudden Death (n = 1,161)
Moderate or severe pain	20.9 (9.7, 32.9)	11.2 (-5.8, 31.2)	15.9 (-1.3, 37.0)	13.3 (-16.6, 53.9)	24.3 (-6.6, 66.4)
Any pain	23.3 (13.4, 33.9)	13.0 (-2.6, 31.3)	22.5 (7.0, 41.7)	18.4 (-8.5, 55.2)	32.8 (5.3, 68.9)
Depression	28.0 (15.7, 42.0)	11.5 (-9.8, 36.7)	25.0 (6.4, 46.7)	37.6 (8.2, 78.0)	23.1 (-7.8, 64.6)
Periodic confusion	28.8 (15.6, 43.6)	26.7 (-2.4, 61.5)	16.5 (-2.4, 39.0)	20.1 (5.0, 39.0)	49.4 (3.4, 114.8)
Dyspnea	13.1 (2.5, 24.5)	5.0 (-15.4, 27.9)	2.5 (-7.0, 13.1)	9.1 (-26.2, 56.1)	42.4 (6.6, 92.6)

	Adjusted % Change (95% CIs)				
	Models adjusted for demographics and clinical, psychological, social, and proxy characteristics[b]				
Outcome	Entire Population (n = 7,204)	Cancer (n = 1,546)	CHF or Chronic Lung Disease (n = 2,293)	Frailty (n = 1,175)	Sudden Death (n = 1,161)
Incontinence	10.4 (-0.6, 23.3)	-9.9 (-29.6, 16.6)	3.0 (-14.4, 23.4)	-1.9 (-18.7, 16.8)	48.2 (4.9, 113.5)
Severe fatigue	8.7 (0.3, 17.6)	3.4 (-8.8, 17.7)	0.7 (-10.8, 14.1)	-2.2 (-23.1, 24.3)	21.3 (-6.6, 59.3)
Anorexia	8.7 (0.5, 17.5)	8.1 (-3.3, 20.4)	1.2 (-10.5, 14.3)	-6.0 (-21.9, 12.0)	21.2 (-11.6, 63.9)
Frequent vomiting	5.1 (-20.8, 40.3)	25.7 (-16.9, 91.4)	-29.4 (-60.9, 27.2)	-16.3 (-63.2, 93.6)	105.5 (-13.9, 457.9)

[a] Analysis accounts for complex survey design

[b] Adjusted percent change is predicted from regression models of each symptom on time of death, controlling for age at death, gender, race/ethnicity, number of nights spent in a hospital in the last two years of life, nursing home residency at the time of death and length of nursing home residency prior to death (regardless of site of death), number of ADL dependencies (0–6 scale), diagnosis of arthritis (pain models only), depression reported in interview wave prior to death, highest level of education, household wealth, household income, proxy relationship to decedent, time elapsed between decedent's death and proxy's interview, average hours per week of care given to decedent from all informal carers, highest level of education if proxy was spouse, English/Spanish preference for interview, and year that the decedent entered the HRS sample. Confidence intervals are bootstrapped.

[c] Adjusted percent change is predicted from regression models of each symptom on time of death, controlling for age at death, gender, race/ethnicity, and time elapsed between decedent's death and proxy's interview. Confidence intervals are bootstrapped.