Published in final edited form as:

Ann Intern Med. 2010 November 2; 153(9): 563–569. doi:10.1059/0003-4819-153-9-201011020-00005.

The Epidemiology of Pain During the Last Two Years of Life

Alexander K. Smith, MD, MS, MPH^{1,2}, Irena Stijacic Cenzer, MA¹, Sara J. Knight, PhD^{2,3}, Kathleen A. Puntillo, RN, DNSc⁴, Eric Widera, MD^{1,2}, Brie A. Williams, MD^{1,2}, W. John Boscardin, PhD, and Kenneth E. Covinsky, MD, MPH^{1,2}

¹Division of Geriatrics, Department of Medicine, University of California, San Francisco, San Francisco, CA

²Veterans Affairs Medical Center, San Francisco, CA

³Departments of Psychiatry and Urology, University of California, San Francisco, San Francisco, CA

⁴Department of Physiological Nursing, University of California, San Francisco, San Francisco, CA

Abstract

Background—The epidemiology of pain during the last years of life has not been well described.

Objective—To describe the prevalence and correlates of pain over the last two years of life.

Design—Observational study. We analyzed data from subjects who died while enrolled in the Health and Retirement Study. The survey interview closest to death was used. Each subject or proxy was interviewed once in the last 24 months of life and were classified into one of 24 cohorts based on the number of months between the interview and death. We modeled the relationship between time before death and pain adjusted for age, gender, race/ethnicity, education, net worth, income, terminal diagnosis category, arthritis, and proxy status.

Setting—The Health and Retirement Study, a nationally representative survey of community-living older adults (1994–2006).

Participants—Older adult decedents.

Measurements—Significant pain as indicated by a report that the subject was “often troubled” by pain of at least moderate severity.

Results—The sample included 4,703 decedents (mean age [SD] 75.7 [10.8], 83.1% white, 10.7% black, 4.7% Hispanic, 52.3% men). The adjusted prevalence of pain 24 months prior to death was 26% (95% CI, 23–30%). The prevalence remained flat until 4 months prior to death (28%, 25–32%), then increased, reaching 46% (38–55%) in the last month of life. The prevalence of pain in the last month of life was 60% among patients with arthritis vs. 26% among patients without arthritis ($p<.001$), and did not differ by terminal diagnosis category (cancer 45%, heart disease 48%, frailty 50%, sudden death 42%, other 47%, $p=0.195$).

Limitations—cross sectional data; 19% proxy responses; information about cause, location, and treatment of pain not available.

Address for reprint requests: Alexander K. Smith, MD, MS, MPH Division of Geriatrics, UCSF 4150 Clement St (181G) San Francisco, CA 94121 Voice: 415-221-4810 x 4684, Fax: 415-750-6641 aksmith@ucsf.edu..

Current mailing addresses for all authors: Irena Stijacic Cenzer, Sara Knight, Eric Widera, Brie Williams, W. John Boscardin, and Kenneth Covinsky is the same: San Francisco VA Medical Center 4150 Clement St. San Francisco, CA 94121

The address for Kathleen Puntillo is: Department of Physiological Nursing 2 Koret Way, Box 0610 University of California, San Francisco 94143-0610

Conclusions—While the prevalence of pain increases in the last 4 months of life, pain is present in over a quarter of elders over the last 2 years of life. Arthritis is strongly associated with pain at the end of life.

Primary Funding Source—National Institute on Aging; National Center for Research Resources; National Institute on Musculoskeletal and Skin Diseases; National Palliative Care Research Center.

Introduction

Pain exerts a profoundly negative impact on patients' quality of life at the end of life (1–3). Freedom from pain was rated as one of the most important of 44 potential factors related to a good death in a national survey of seriously ill patients, bereaved family members, and health care providers (4). As patients approach the last years of life, goals of care focus more on quality of life -- and management of symptomatic distress, especially pain, may become more important than disease management.

While most people would view being free of significant pain as a high priority for their last years, we know very little about the prevalence of pain towards the end of life, although it is assumed to increase as death nears. However, this belief is generally based on research reporting high rates of pain in persons in the last days to weeks of life (5). Few studies have compared pain prevalence at multiple intervals in the last months of life. Most longitudinal studies have been limited to highly selected populations such as persons with cancer (5–7), or hospice patients (8, 9), and have not been representative of the general population of decedents. Several studies have asked bereaved family members to recall how much pain was experienced by their family member at the end of life (10–12). While these retrospective reports are useful, it has also been noted that these types of studies are highly prone to bias (13). The usual recall bias of retrospective studies is compounded by the effect of grieving on perceptions after a loved one's death (14).

Substantial logistical challenges make population-based studies of pain at the end of life exceedingly difficult to conduct. In particular it is difficult to know how soon the death will occur, especially from non-cancer causes. Limiting studies to patients with cancer, however, misses the majority of adults who die with frailty, organ failure, or other illnesses characterized by prognostic uncertainty (15). To address these limitations, we examined significant pain (i.e. moderate or severe) in subjects who died while in the Health and Retirement Study (HRS), a nationally representative study of adults over the age of 50. By using the last subject interview before death, we present the first population based data on the prevalence of significant pain in monthly intervals over the last two years of life for different groups of respondents. As a point of reference, we compared the prevalence of significant pain in the last two years of life to the background prevalence of pain among subjects of the same age who did not die. We also explored the association between reports of significant pain and demographic, socio-economic, and clinical factors. We were particularly interested in exploring the influence of arthritis, given its high prevalence among older adults (16).

Methods

Setting and Participants

The HRS had conducted interviews every two years, starting in 1992, with the goal of examining changes in wealth and health as people transition from work to retirement and old age. The one hour HRS interviews were conducted primarily by phone, but face-to-face interviews were conducted for most subjects who were: aged 80 and older, too ill to

participate in the telephone interview, or unable to access a phone. The HRS uses a national area probability sample of U.S. households, with supplemental oversamples of Blacks, Hispanics and residents of the state of Florida. Details of the complex study design and data collection procedures are available (17). We included subjects who died while enrolled in HRS and who provided information about presence of pain in an interview within two years of their death.

A total of 26,977 eligible subjects were enrolled at HRS between 1994 (the first year that the pain question was asked) and 2006 (the latest year with available data), and 6,664 subjects died while enrolled in the study. We excluded 759 subjects who resided in the nursing home rather than the community at the time of their last interview. One hundred ninety seven deceased subjects did not have a date of death, and were excluded. Two deceased subjects were removed because their reported date of death preceded their last reported core interview. We used the interview dates to determine the length of time (in months) between the interview when the pain question was asked and death. Of the remaining 5,706 subjects, 971 had their last interview more than 24 months before their death, and another 32 did not completely answer the pain questions (item response 99.3%). The remaining 4,703 subjects represent our final analytic sample.

Subjects were placed into one of 24 cohorts based on the time interval between the last interview and death. Using the exact dates of interview and death, each cohort consisted of subjects interviewed in 30 day intervals (hereafter referred to as months) before death with from 2.6% to 4.8% of the sample interviewed within a 30 day interval. To provide a comparison for the background prevalence of pain, we determined the prevalence of pain among the 16,963 subjects enrolled in HRS who were alive in 2006 and responded to the pain questions.

This study was approved by the Institutional Review Board of the University of California, San Francisco.

Outcome: Significant Pain

The presence of significant pain was determined using two questions. In the first question, subjects were asked, “Are you often troubled with pain?” Subjects who responded “Yes” were asked the follow-up question, “How bad is the pain most of the time: mild, moderate or severe?” Subjects who responded “moderate” or “severe” were classified as experiencing significant pain. We chose this classification of pain for two reasons. First, moderate or severe pain should trigger a clinical response, including consideration of opioid therapy, according to the American Geriatrics Society Guidelines for the Pharmacological Management of Persistent Pain in Older Adults and the National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology (18, 19). Second, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) used this approach to categorize reports of pain at the end of life (10). When subjects were too ill to respond directly to the interview, the next of kin (proxy) was asked to rate the subject's level of pain. The proportion of proxy respondents varied from 16% at 24 months prior to death to 33% in the last month of life.

Other Measures

Our secondary aim was to examine correlates of significant pain over the last 2 years of life. We considered factors that, based on prior studies, could be associated with significant pain (20–22). Those factors included self-reported age, gender, race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, and other), educational attainment, income, net worth, and arthritis. We used a sequential categorization scheme to group subjects into one of five

terminal diagnosis categories based on after-death interviews with subjects' next of kin, using a previously described method (15, 23, 24). Briefly, subjects who died within 1 day of the diagnosis of their terminal illness were categorized as having a “sudden death”. For the remaining subjects, deaths were classified as from cancer, heart disease, or being frail. Subjects were considered frail when death occurred in a nursing home, after a hip fracture in their last year of life, or with physician-diagnosed memory impairment (assessed in surveys after 1998). The remaining subjects were grouped in “other.” Of the 4,703 subjects in our study, we had information on the terminal diagnosis category for 4,475 subjects who constituted our sample for secondary analyses related to cause of death.

Statistical Analysis

All reported analyses were weighted for the differential probability of selection and take into account the complex design of HRS. Our primary study question, the prevalence of significant pain in the last two years of life, was examined graphically by plotting the prevalence of significant pain among in the 24 cohorts against time. To determine whether the prevalence of pain differed over the last 2 years, we examined the fit of several functional forms for the relationship between pain and time. We examined whether the relationship between pain and time was linear or nonlinear using spline models that accounted for the possibility that the slope of the pain-time relationship could change as death approached. We tested spline models with interior knots at 2, 3, 4 and 5 months before death. In order to identify the model that best fit our data, we first checked for overall lack of fit using a recent extension of the Hosmer-Lemeshow test that accounts for the complex survey design (25). Next, to compare candidate models, we computed approximate AIC and BIC statistics, weighted for differential probability of selection but without adjustment for the complex design. Lastly, we examined standard logistic regression residual plots and influence diagnostics for our selected unadjusted and adjusted models (26). To determine whether changes in pain over time were due to confounding, we estimated a multivariable model adjusting for age, gender, race/ethnicity, education, net worth, income, terminal diagnosis category, arthritis, and proxy status. Residuals plots for both the unadjusted and adjusted models were consistent with an appropriate functional form for our data, and model diagnostic checks did not highlight any influential cases.

To address a secondary question about differences in the prevalence of significant pain among subgroups, we examined our multivariable models at 4 time points prior to death (i.e. 2 years, 1 year, 4 months, and the last month). For ease of interpretation, we calculated predicted probabilities of pain by level of each independent variable using the final multivariable model and fixing all other model terms at the population means. When estimating predicted probabilities by age, we used a model that did not include terms for terminal diagnosis category and arthritis because we wanted to adjust for potentially confounding factors but not for diseases associated with aging. To examine whether the presence of arthritis had differential effects by terminal diagnosis group, we tested for an interaction between these factors in our multivariable model.

The statistical analyses were performed using STATA10.1 software (StataCorp. 2007. Stata Statistical Software: Release 10. College Station, TX: StataCorp LP.), and SAS 9.2 software (SAS software, Version 9.2 of the SAS System for Windows, Copyright 2008, SAS Institute Inc., Cary, NC, USA).

Role of the Funding Source

This research was supported by National Institute on Aging (NIA), the National Center for Research Resources (NICCR), the National Institute on Musculoskeletal and Skin Diseases (NIAMS), and the National Palliative Care Research Center (NPCRC). The NIA, NCRR,

NIAMS, and NPCRC had no role in the design, conduct, or analysis of this study or in the decision to submit the manuscript for publication.

Results

Among the 4,703 study participants, the mean age was 76 and 52% were men (Table 1). The median net worth was \$89,000 but the median household income was only \$20,000. The most common terminal diagnosis category was heart disease (29.7%), followed by cancer (27.6%), sudden death (16.7%), other causes (14.2%) and frailty (11.8%).

The prevalence of significant pain rose from 30.7% (95% CI, 21.2–40.1%) among subjects interviewed two years prior to death to 47.4% (37.0–57.8%) among subjects interviewed in the last month (Figure). The background prevalence of pain among the 16,963 subjects who were alive in 2006 was 24.2% (95% CI, 23.4–25.0%) which was lower than the 30.9% (95% CI, 29.3–32.6%) prevalence in the subjects interviewed at any point within two years of death ($p < 0.001$).

In our multivariable model, the best functional form for time was a spline with a single interior knot at 4 months prior to death. From this model, the predicted prevalence of significant pain was 26% (95% CI, 23–30%) 24 months prior to death (Table 2). Over the next 20 months, the predicted prevalence of significant pain rose slightly from 26% to 28%, though the slope of the fitted line did not differ from 0 ($p = 0.54$) but, in last 4 months of life it increased from 28% to 46% (average of 6.0 percentage point increase per month, a slope which did differ from 0, $p < 0.001$). These results were similar before and after adjustment for all covariates.

After adjustment for covariates, significant differences in the predicted prevalence of pain were observed for: age, gender, race/ethnicity, net worth, proxy status, and arthritis (Table 2). The prevalence of pain decreased with each decade above age 65 compared with younger than 65. Among subjects ≤ 65 , the predicted prevalence of pain was 39% 2 years prior to death compared to 23% among subjects ≥ 86 , and this difference was maintained in the last month of life (60% vs. 42%). Further adjustment of models of age for arthritis widened these differences by age (not shown). The predicted prevalence of pain was higher in women than men at all four time points. Compared with whites, Hispanic subjects had similar predicted probabilities of significant pain but African Americans were less likely to report significant pain. Patients with net worth less than or equal to the median value (\$89,000) were more likely to report significant pain than those with a higher net worth. Proxy reporting was also associated with more reports of significant pain. However, pain did not differ significantly by terminal diagnosis category.

The presence of arthritis appeared to have the greatest differential in the predicted prevalence of significant pain at all time points (Table 2). In an analysis of subjects who were alive in 2006 (not shown), a similar magnitude difference was observed with 36% of subjects with arthritis having significant pain versus 10% of those without arthritis ($p < .001$). The interaction between arthritis and terminal diagnosis category was not significant (p -interaction = .10).

Discussion

In a nationally representative cohort of older adults, we examined significant pain in 24 different monthly cohorts of subjects or their proxies who were interviewed within 2 years of the subject's death. We observed that the prevalence of pain changed little until four months prior to death, when it steadily increased through the last month of life. As patients approach death, our data support frequent monitoring and adjustment of pharmacologic and

non-pharmacologic treatments (e.g. massage, physical therapy) (27, 28). However, physicians are notoriously poor at predicting when patients have only a few months to live (29–31). Because significant pain was reported by at least one quarter of subjects in each of the last 24 months of life, it is incumbent upon the physician to assess and address pain in patients with chronic diseases but who are not clearly nearing death.

Our study raises a number of questions for future study that we were not able to address. The HRS does not include questions about treatment of pain. Therefore, we do not know the extent to which reported pain was due to physician factors such as under-diagnosis or under-treatment (2, 32), system factors such as access to affordable and effective analgesics (33), or patient factors such as non-adherence (34). Previous studies have reported decreasing prevalence of significant pain with older age (35–39). The reliability of reports of significant pain by the oldest subjects may have been compromised by cognitive factors (40), differences in pain tolerance (41, 42), or differential response to analgesic medications (39). Measurement error is another potential explanation for lower reports of pain with age, with less reliable reports of pain by older persons (43). Similarly, while differences have previously been reported by gender (42), race/ethnicity (42, 44), and wealth (22, 45), the underlying reasons for these differences could not be addressed in this study.

The prospectively reported prevalence of significant pain in the last months of life reported here builds on the foundation from several other studies. For conscious patients who died in the hospital in SUPPORT, 50% of family members interviewed after the death reported that their loved one experienced moderate or severe pain at least half the time in the last three days of life (46). In a population-based mortality follow-back survey of cancer deaths in the United Kingdom, family members reported 88% of decedents experienced pain of any severity at some point in the last year of life, and 66% in the last week of life (12). In a cross sectional study of 988 patients with terminal illness, 50% reported moderate or severe pain, without any difference by terminal diagnosis observed (47). In interviews with caregivers of decedents in HRS, caregivers reported that 52% of patients had 'often' experienced pain in the last year of life (22). We were able to offer additional information about pain at the end of life by reporting results of interviews with a nationally representative sample of community-based individuals and our analysis of pain at specific time intervals before death.

These findings have implications for clinical care. Clinicians should anticipate an increase in pain especially as death nears with appropriate modification of pharmacologic and non-pharmacologic therapies. Primary care clinicians should consider referring elders with difficult to manage pain to pain or palliative medicine specialists. Despite increasing recognition that pain in later life constitutes a major public health issue (48), older individuals are dramatically under-represented in specialty pain clinics (49). Subjects with arthritis suffer much more than those who do not have arthritis. This differential may reflect the negative effects of mobility impairments. In the elderly, pain is more likely to occur in joints (35), has detrimental effects on daily activities (50), and is associated with depression (51) and social isolation (48). Pain in the elderly may be similar to other geriatric syndromes that are multifactorial in etiology and impact, and are optimally treated with a multifaceted approach. Even in elders with a dominant life-limiting diagnosis, management of pain may require careful consideration of ongoing chronic problems such as arthritis, which may have an even greater effect on quality of life than the life-limiting diagnosis (52).

This study has several limitations. First, the HRS does not include questions about the cause, location, or treatment of pain. Patients may misinterpret what is pain from arthritis and may describe any musculoskeletal pain, even from bone metastases, as "arthritis" pain. Second, 19% of subjects in our sample were too sick to be interviewed, and in these cases we relied on proxy data about pain from subjects' next of kin. The proportion of subjects with a proxy

report was higher among groups of subjects interviewed closer to death, and as in other studies, proxy status was associated with a higher report of pain (13). However, in our clinical experience physicians rely on family members to provide proxy information about pain when the patient is too ill to respond, and the relationship between pain and time was similar after adjustment for proxy status. Finally, an ideal study of the prevalence of pain would follow the same group of patients over time with periodic interviews to truly capture the trajectory of pain as one nears death. Such a study would be prohibitively expensive to conduct on a population based scale. In the absence of such data, we were able to use prospectively collected data from subjects sampled at varying time points in the last years of life.

In conclusion, significant pain at the end of life is common. The prevalence is high two years before death, and increases substantially only in the last 4 months of life. Given current challenges to accurate prognostication, in general clinicians should focus as much on the management of pain in patients with chronic illness as in patients with clearly terminal disease.

Acknowledgments

The authors would like to thank Jessamyn Conell-Price, BA, for her assistance in preparing this manuscript for publication. Abstract versions of this work were presented at the Annual Meeting of the American Geriatrics Society in Chicago, 2009, and the Annual Meeting of the Society of General Internal Medicine in Miami, 2009.

Grant Support: Dr Smith is supported by a Research Supplement to Promote Diversity in Health Related Research from the National Institute on Aging (R01AG028481), the National Center for Research Resources UCSF-CTSI (UL1 RR024131), and the National Palliative Care Research Center. Dr. Covinsky is supported by a K-24 from the National Institute on Aging (K24AG029812) and the National Institute on Musculoskeletal and Skin Diseases (P60 AR053308).

REFERENCES

1. Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. *J Pain Symptom Manage*. 1999; 17(2):93–108. [PubMed: 10069149]
2. Bernabei R, Gambassi G, Lapane K, Landi F, Gatsonis C, Dunlop R, Lipsitz L, Steel K, Mor V. Management of pain in elderly patients with cancer. SAGE Study Group. Systematic Assessment of Geriatric Drug Use via Epidemiology. *Jama*. 1998; 279(23):1877–82. [see comments] [published erratum appears in *JAMA* 1999 Jan 13;281(2):136]. [PubMed: 9634258]
3. Lloyd-Williams M, Dennis M, Taylor F. A prospective study to determine the association between physical symptoms and depression in patients with advanced cancer. *Palliat Med*. Sep; 2004 18(6): 558–63. [PubMed: 15453627]
4. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *Jama*. Nov 15; 2000 284(19):2476–82. [PubMed: 11074777]
5. Ventafridda V, Ripamonti C, De Conno F, Tamburini M, Cassileth BR. Symptom prevalence and control during cancer patients' last days of life. *J Palliat Care*. 1990; 6(3):7–11. [PubMed: 1700099]
6. Mercadante S, Casuccio A, Fulfaro F. The course of symptom frequency and intensity in advanced cancer patients followed at home. *J Pain Symptom Manage*. 2000; 20(2):104–12. [PubMed: 10989248]
7. Conill C, Verger E, Henriquez I, Saiz N, Espier M, Lugo F, Garrigos A. Symptom prevalence in the last week of life. *J Pain Symptom Manage*. 1997; 14(6):328–31. [PubMed: 9409097]
8. Dobratz MC, Wade R, Herbst L, Ryndes T. Pain efficacy in home hospice patients. A longitudinal study. *Cancer Nurs*. 1991; 14(1):20–6. [PubMed: 2013048]
9. Owens MR, Simmons B, Gibson PS, Weeks D. A longitudinal study of pain in hospice and pre-hospice patients. *Am J Hosp Palliat Care*. 2001; 18(2):124–8. [PubMed: 11407128]

10. Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J, Claessens MT, Wenger N, Kreling B, Connors AF Jr. Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Ann Intern Med.* 1997; 126(2):97–106. see comments. [PubMed: 9005760]
11. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V. Family perspectives on end-of-life care at the last place of care. *Jama.* Jan 7; 2004 291(1):88–93. [PubMed: 14709580]
12. Addington-Hall J, McCarthy M. Dying from cancer: results of a national population-based investigation. *Palliat Med.* 1995; 9(4):295–305. [PubMed: 8548091]
13. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? *Soc Sci Med.* Jan; 2003 56(1):95–109. [PubMed: 12435554]
14. Higginson I, Priest P, McCarthy M. Are bereaved family members a valid proxy for a patient's assessment of dying? *Soc Sci Med.* Feb; 1994 38(4):553–7. [PubMed: 7514313]
15. Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. *Jama.* May 14; 2003 289(18):2387–92. [PubMed: 12746362]
16. Dunlop DD, Manheim LM, Song J, Chang RW. Arthritis prevalence and activity limitations in older adults. *Arthritis Rheum.* Jan; 2001 44(1):212–21. [PubMed: 11212163]
17. Health and Retirement Study: Survey Design. [July 10, 2009]; Available from: <http://hrsonline.isr.umich.edu/sitedocs/surveydesign.pdf>
18. American Geriatrics Society Guidelines for the Pharmacological Management of Persistent Pain in Older Adults. [July 10, 2009]; Available from: https://vpn.ucsf.edu/education/DanaInfo=www.americangeriatrics.org+pharm_management.shtml
19. National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology: Adult Cancer Pain. [July 10, 2009]; Available from: http://www.nccn.org/professionals/physician_gls/PDF/pain.pdf
20. Bernabei R, Gambassi G, Lapane K, Landi F, Gatsonis C, Dunlop R, Lipsitz L, Steel K, Mor V. Management of pain in elderly patients with cancer. SAGE Study Group. Systematic Assessment of Geriatric Drug Use via Epidemiology. *JAMA.* Jun 17; 1998 279(23):1877–82. [PubMed: 9634258]
21. Desbiens NA, Wu AW, Broste SK, Wenger NS, Connors AF Jr, Lynn J, Yasui Y, Phillips RS, Fulkerson W. Pain and satisfaction with pain control in seriously ill hospitalized adults: findings from the SUPPORT research investigations. For the SUPPORT investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Crit Care Med.* 1996; 24(12):1953–61. see comments. [PubMed: 8968261]
22. Silveira MJ, Kabeto MU, Langa KM. Net worth predicts symptom burden at the end of life. *J Palliat Med.* Aug; 2005 8(4):827–37. [PubMed: 16128657]
23. Hogan C, Lunney J, Gabel J, Lynn J. Medicare beneficiaries' costs of care in the last year of life. *Health Aff (Millwood).* Jul-Aug; 2001 20(4):188–95. [PubMed: 11463076]
24. Lunney JR, Lynn J, Hogan C. Profiles of older medicare decedents. *J Am Geriatr Soc.* Jun; 2002 50(6):1108–12. [PubMed: 12110073]
25. Archer KJ, Lemeshow S. Goodness-of-fit test for a logistic regression model fitted using survey sample data. *The Stata Journal.* 2006; 6(1):97–105.
26. Hosmer, DW.; Lemeshow, S. Applied logistic regression. Second ed.. John Wiley & Sons; New York: 2000.
27. Kutner JS, Smith MC, Corbin L, Hemphill L, Benton K, Mellis BK, Beaty B, Felton S, Yamashita TE, Bryant LL, Fairclough DL. Massage therapy versus simple touch to improve pain and mood in patients with advanced cancer: a randomized trial. *Ann Intern Med.* Sep 16; 2008 149(6):369–79. [PubMed: 18794556]
28. Scheetz J, Shell B. Physical therapy in the symptomatic management of pain. *Dimens Oncol Nurs.* 1988; 2(3):9–13. [PubMed: 3266958]
29. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *Bmj.* Feb 19; 2000 320(7233):469–72. [PubMed: 10678857]

30. Glare P, Virik K, Jones M, Hudson M, Eychmuller S, Simes J, Christakis N. A systematic review of physicians' survival predictions in terminally ill cancer patients. *Bmj*. Jul 26.2003 327(7408): 195. [PubMed: 12881260]
31. Christakis, N. *Death Foretold: Prophecy and Prognosis in Medical Care*. University of Chicago Press; Chicago, IL: 2001.
32. Cleeland CS, Gonin R, Hatfield AK, Edmonson JH, Blum RH, Stewart JA, Pandya KJ. Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med*. 1994; 330(9):592–6. [PubMed: 7508092]
33. Morrison RS, Wallenstein S, Natale DK, Senzel RS, Huang LL. “We don't carry that”--failure of pharmacies in predominantly nonwhite neighborhoods to stock opioid analgesics. *N Engl J Med*. Apr 6; 2000 342(14):1023–6. [PubMed: 10749965]
34. Du Pen SL, Du Pen AR, Polissar N, Hansberry J, Kraybill BM, Stillman M, Panke J, Everly R, Syrjala K. Implementing guidelines for cancer pain management: results of a randomized controlled clinical trial. *J Clin Oncol*. 1999; 17(1):361–70. [PubMed: 10458255]
35. Helme RD, Gibson SJ. The epidemiology of pain in elderly people. *Clin Geriatr Med*. Aug; 2001 17(3):417–31. v. [PubMed: 11459713]
36. Desbiens NA, Wu AW, Broste SK, Wenger NS, Connors AF Jr. Lynn J, Yasui Y, Phillips RS, Fulkerson W. Pain and satisfaction with pain control in seriously ill hospitalized adults: findings from the SUPPORT research investigations. For the SUPPORT investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatmentm. *Crit Care Med*. Dec; 1996 24(12):1953–61. [PubMed: 8968261]
37. Desbiens NA, Mueller-Rizner N, Connors AF Jr. Hamel MB, Wenger NS. Pain in the oldest-old during hospitalization and up to one year later. HELP Investigators. Hospitalized Elderly Longitudinal Project. *J Am Geriatr Soc*. Oct; 1997 45(10):1167–72. [PubMed: 9329476]
38. Harkins SW, Price DD, Martelli M. Effects of age on pain perception: thermonociception. *J Gerontol*. Jan; 1986 41(1):58–63. [PubMed: 3941257]
39. Bellville JW, Forrest WH Jr. Miller E, Brown BW Jr. Influence of age on pain relief from analgesics. A study of postoperative patients. *JAMA*. Sep 27; 1971 217(13):1835–41. [PubMed: 5109724]
40. Reynolds KS, Hanson LC, DeVellis RF, Henderson M, Steinhauer KE. Disparities in pain management between cognitively intact and cognitively impaired nursing home residents. *J Pain Symptom Manage*. Apr; 2008 35(4):388–96. [PubMed: 18280101]
41. Harkins SW, Chapman CR. Detection and decision factors in pain perception in young and elderly men. *Pain*. Sep; 1976 2(3):253–64. [PubMed: 1026903]
42. Woodrow KM, Friedman GD, Siegelaub AB, Collen MF. Pain tolerance: differences according to age, sex and race. *Psychosom Med*. Nov-Dec; 1972 34(6):548–56. [PubMed: 4644663]
43. Pharmacological management of persistent pain in older persons. *J Am Geriatr Soc*. Aug; 2009 57(8):1331–46. [PubMed: 19573219]
44. Edwards RR, Doleys DM, Fillingim RB, Lowery D. Ethnic differences in pain tolerance: clinical implications in a chronic pain population. *Psychosom Med*. Mar-Apr; 2001 63(2):316–23. [PubMed: 11292281]
45. Schludermann E, Zubek JP. Effect of age on pain sensitivity. *Percept Mot Skills*. 1962; 14:295–301.
46. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *Jama*. Nov 22-29; 1995 274(20):1591–8. [PubMed: 7474243]
47. Weiss SC, Emanuel LL, Fairclough DL, Emanuel EJ. Understanding the experience of pain in terminally ill patients. *Lancet*. 2001; 357(9265):1311–5. [PubMed: 11343734]
48. Peat G, Thomas E, Handy J, Croft P. Social networks and pain interference with daily activities in middle and old age. *Pain*. Dec; 2004 112(3):397–405. [PubMed: 15561396]
49. Pappagallo, M., editor. *The Neurologic Basis of Pain*. 1st ed.. McGraw-Hill Professional; New York, NY: 2004.

50. Thomas E, Peat G, Harris L, Wilkie R, Croft PR. The prevalence of pain and pain interference in a general population of older adults: cross-sectional findings from the North Staffordshire Osteoarthritis Project (NorStOP). *Pain*. Jul; 2004 110(1–2):361–8. [PubMed: 15275787]
51. Turk DC, Okifuji A, Scharff L. Chronic pain and depression: role of perceived impact and perceived control in different age cohorts. *Pain*. Apr; 1995 61(1):93–101. [PubMed: 7644253]
52. Dominick KL, Ahern FM, Gold CH, Heller DA. Health-related quality of life among older adults with arthritis. *Health Qual Life Outcomes*. 2004; 2:5. [PubMed: 14720300]

Figure.

Frequency of Significant Pain over the Last Two Years of Life. Diamonds represent the mean prevalence of significant pain (defined as often experiencing moderate or severe pain) at each monthly interval prior to death; bars represent 95% confidence intervals.

Table 1

Characteristics of study sample (n=4,703)

Characteristic		Value *
Demographics	Age, %	
	≤ 65	21.0
	66–75	23.8
	76–85	36.2
	≥ 86	18.9
	Male, %	52.3
	Race / Ethnicity, %	
	White	83.1
	Black	10.7
	Hispanic	4.7
	Other	1.6
Socio-economic measures [†]	< High School Diploma, %	38.0
	Net worth, median (IQR)	89K (17K – 240K)
	Income, median (IQR)	20K (11K – 37K)
Terminal Diagnosis Category [‡]	Cancer, %	27.6
	Heart Disease, %	29.7
	Frailty, %	11.8
	Sudden Death, %	16.7
	Other, %	14.2
Other health [‡]	Arthritis, %	62.2

* Reported values incorporate survey weights to account for the complex survey design.

[†] Assessed in the last interview before death.[‡] Assessed in after death interviews with next of kin.

Table 2

Predicted Prevalence of Pain At Four Time Points Before Death for Various Subgroups*

Characteristic	Two Years		One Year		Four Months		Last Month		p-value [†]	Global p-value [‡]
	%	95% CI	%	95% CI	%	95% CI	%	95% CI		
Total Population	26	(23,30)	27	(25,30)	28	(25,32)	46	(38,55)	-	-
Age[§]										
≤ 65	39	(33,45)	40	(35,45)	41	(35,47)	60	(50,70)	-	<0.001
66–75	31	(26,35)	31	(28,35)	32	(28,37)	51	(43,59)	0.007	
76–85	27	(23,31)	28	(26,31)	29	(25,32)	47	(39,55)	<0.001	
≥ 86	23	(19,28)	24	(21,27)	25	(21,28)	42	(33,51)	<0.001	
Men	23	(20,27)	24	(22,27)	25	(21,29)	42	(34,51)	0.001	
Women	30	(26,34)	31	(28,34)	32	(28,36)	50	(41,60)		
Race / Ethnicity										
White	27	(24,31)	28	(26,31)	29	(25,33)	47	(39,56)	-	0.016
Black	19	(15,25)	20	(16,25)	21	(16,26)	37	(27,48)	0.005	
Hispanic	30	(24,37)	31	(25,38)	32	(25,40)	51	(40,62)	0.35	
Other	20	(11,35)	21	(11,36)	22	(11,37)	38	(21,59)	0.31	
≥High School Diploma	26	(23,29)	27	(25,29)	27	(24,31)	46	(37,55)	0.40	
<High School Diploma	27	(23,32)	28	(25,32)	29	(25,34)	47	(39,56)		
Net worth >89K	24	(21,27)	25	(22,28)	26	(21,30)	43	(34,52)	0.003	
Net worth ≤89K	29	(25,33)	30	(28,33)	31	(27,34)	49	(41,58)		
Income >20K	26	(22,31)	27	(25,30)	28	(24,32)	46	(37,55)	0.89	
Income ≤20K	27	(23,30)	28	(24,31)	28	(24,33)	46	(37,56)		
Terminal diagnosis Category										
Cancer	25	(21,30)	26	(23,30)	27	(23,32)	45	(36,54)	-	0.195
Heart Disease	27	(23,33)	28	(25,32)	29	(25,34)	48	(38,58)	0.36	
Frailty	30	(25,35)	31	(26,36)	31	(25,38)	50	(40,60)	0.079	
Sudden Death	23	(19,28)	24	(21,28)	25	(21,30)	42	(33,52)	0.37	

Characteristic	Two Years		One Year		Four Months		Last Month		p-value [†]	Global p-value [‡]
	%	95% CI	%	95% CI	%	95% CI	%	95% CI		
Other	27	(23,32)	28	(24,34)	29	(23,36)	47	(38,58)	0.54	
Arthritis	38	(34,42)	39	(37,42)	40	(36,44)	60	(51,68)	<0.001	
No Arthritis	13	(10,15)	13	(11,16)	14	(11,17)	26	(20,33)		
Proxy	34	(28,41)	36	(31,40)	36	(31,41)	56	(47,64)	<0.001	
No Proxy	25	(22,28)	26	(23,28)	26	(23,30)	44	(35,53)		

The spline model included a single interior knot at 4 months prior to death (p-value for the increase in significant pain over the first 20 months prior to the knot = 0.54; p-value for the increase in significant pain over the last 4 months after the knot <0.001).

* Predicted prevalence values are the predicted probabilities from the multivariable spline model with terms for all the variables presented in the table. Predicted probabilities are calculated with all other variables in the model held constant at their population means.

[†] p-value compares results for the specific sub-group to the reference group, based upon the final multivariable logistic model.

[‡] global p-value expresses significance across the subgroup categories

[§] Models for age are not adjusted for arthritis or terminal diagnosis category.