

Increased Family Reports of Pain or Distress in Dying Oregonians: 1996 to 2002

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ABSTRACT

The aim of this study was to compare the prevalence of family-reported pain or distress during the last week of decedents' lives during two times: November 1996 to December 1997 and June 2000 to March 2002. We telephone-surveyed family caregivers of Oregonians who had died 2 to 5 months previously in private homes, nursing homes, and other community-based settings. Caregivers were asked to rate the level of pain or distress during the decedent's final week of life on a four-point scale. Data were collected from 340 respondents from 1996–1997 and 1384 respondents from 2000–2002. We found that the prevalence of family-reported moderate or severe pain or distress (compared to comfortable or mild pain or distress) in Oregon decedents increased from 30.8% in 1996–1997 to 48% in 2000–2002. Using a logistic regression model to control for differences between the two sampling times and other predictors of increased pain or distress, decedents in 2000–2002 remained approximately twice as likely to be reported to be in moderate or severe pain or distress during the last week of their lives (Time 2 vs. Time 1, odds ratio [OR] 2.09, 95% confidence interval [CI] 1.59–2.74). We discuss possible explanations for this finding, including media effect created by the publicity surrounding the second ballot measure and subsequent availability of physician-assisted suicide in November 1997. Alternatively, trends in underfunding and understaffing of hospice and community nursing resources may have disproportionately affected care in the final week of life, which depends heavily on skilled nursing care for effective symptom control and psychosocial support of the patient and family.

INTRODUCTION

THE TREATMENT OF PAIN is well accepted as integral to quality health care for seriously ill patients. For dying patients, the adequate treatment of pain and the relief of suffering necessar-

ily surpass the cure of disease as the primary goals of medical care.¹ Recognizing serious deficiencies in the United States' health care system's ability to ameliorate the pain and suffering of dying patients, multiple organizations including the National Institutes of Health,² the Institute of

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Medicine,³ the American Medical Association,⁴ and the American Nurses' Association⁵ have devoted millions of dollars and countless hours to improving care of the dying nationwide. Similar efforts have been undertaken by the federal government,^{6–8} regulatory agencies,⁹ the Veteran's Health Administration,¹⁰ private foundations,¹¹ and individual states¹² and health care systems.¹³

The key question, increasingly, is whether all these efforts are achieving the desired effect. Unfortunately, the challenges of adequately addressing this question on a large scale are staggering and far beyond our current resources and methodologies.¹⁴ Still, the question is so important—for the good of dying patients and their families, for the proper allocation of resources, and for the advancement of knowledge, that answering it is a priority for research aimed at improving care at the end of life.^{3,15}

Several large studies have documented inadequacies in pain control amongst dying patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)¹⁶ documented that for 50% of conscious patients who died in the hospital, family members reported moderate to severe pain at least half of the time. Unfortunately, SUPPORT also found that patients who preferred that comfort be the primary focus of their care as well as patients who would rather die than be permanently in pain were just as likely to experience severe pain as patients who preferred more aggressive curative therapies during the follow-up period. Data from the Minimum Data Set, a nationally mandated nursing home resident assessment instrument, document that 41.2% of residents in pain at first assessment were also in severe pain 60 to 180 days later.¹⁷

In Oregon, a number of statistics have been cited suggesting that end-of-life care is of good quality overall.¹⁸ Examples include the comparatively high rates of morphine used per 100,000 population,¹⁹ the low rates of in-hospital death,¹⁹ the high rates of hospice enrollment,²⁰ and the finding that 88% of Oregon physician survey respondents had made efforts to improve their knowledge of the use of pain medicines in the terminally ill.²¹

While these statistics are encouraging, data from population-based surveys of Oregon caregivers conducted after a family member's death in-hospital are more worrisome. In these surveys, the prevalence of family-reported moderate to se-

vere pain or distress (compared with comfortable or mild) during the last week of life actually increased from 33% in 1996–1997 to 54% in 1998.²² These findings were based only on deaths that occurred in hospital. Therefore, the aim of this study was to compare the prevalence of family-reported pain or distress during the last week of life in Oregonians who died in community-based settings during two times: November 1996 to December 1997 and June 2000 to March 2002. We defined community-based settings as those outside of the hospital such as private homes, nursing homes, foster care facilities, assisted living, and inpatient hospices.

METHODS

Telephone surveys were conducted 2–5 months after decedents' deaths with 340 respondents in 1996–1997 and 1384 respondents in 2000–2002.

Sample

After approval of Institutional Review Boards at both Oregon Health & Science University and the Oregon Health Division (now the Oregon Department of Human Services), we systematically randomly sampled the death certificates for all Oregon deaths occurring in the 14 months between November 1996 and December 1997 (hereafter called Time 1).²³ We excluded decedents who died in the hospital, who were under the age of 18 years, or who died suddenly without preceding end-of-life care (e.g., sudden cardiac death, suicide, homicide, accident, etc.). Consequently, our Time 1 sampling frame of 24,074 yielded 974 death certificates. We used the same sampling procedure for Time 2, which was the 22 months between June 2000 and March 2002, except that all eligible minority decedents ($n = 779$) were included in the sample frame compared to only 8% of eligible nonminority decedents (i.e., 2269 of 29,130 non-Hispanic Caucasians).²⁴ Less than 5% of Oregon community-based decedents are underrepresented minorities.²⁵ We oversampled minority decedents in Time 2 because Time 1 data lacked sufficient numbers to draw conclusions about possible effects of race or ethnicity.

Respondents were identified using death certificate information and various public and private sources. Case finding techniques were simi-

lar in both studies, although the experience gained in the first study allowed for more effective case finding in the second study.²⁶ Eligible respondents were 18 years or older and reported being “somewhat” or “very” involved in the decedent’s care and decision-making in the last month of life.

Data and instruments

Study data came from death certificates and the telephone interviews of one family respondent per decedent. Trained research assistants (RAs) conducted the interviews. To ensure standardized administration and data recording, each RA interviewed two participants via speaker phone with a project coordinator listening. Both completed the data collection instrument and interrater reliability, as measured by percent agreement, was greater than 94% for Time 1²² and 98.7% (range, 92%–100%) for Time 2.²⁴ These interviews were excluded from subsequent analyses.

The questionnaire instruments used in Time 1 and Time 2 contained different additional questions based on the study aims and hypotheses; however, the data reported here are based on a question that was repeated verbatim and at approximately the same place in the questionnaire (#43 in Time 1 versus #47 in Time 2). The study question was read to each respondent as follows:

Which best describes the level of comfort of <decedent’s name> in the week before his/her death? Would you say that he/she was:

1. Comfortable?
2. In mild pain or distress?
3. In moderate pain or distress?
4. In severe pain or distress?

Whereas the Time 1 instrument contained additional questions about interfacility transfers and whether decedents’ preferences for life sustaining treatments were respected, the Time 2 instrument contained additional questions about advance directives, and the physical, emotional, and financial impact of the death on the decedent’s family members.

To assess the study question’s validity, we compared Time 2 respondents’ answers to the study question with their answers to two items taken from the Memorial Symptom Assessment

Survey, adapted for use with family respondents (F-MSAS).^{27,28} One item assessed the presence or absence of pain during last week of life, while the other item assessed how much distress that pain (if present) caused on a five-point scale (0 = not at all to 4 = very much). These items were not included as part of the main analysis because they were not asked of the Time 1 respondents. We also compared the respondents’ answers to the study question to the Family Memorial Symptom Assessment Survey Global Distress Index (F-MSAS GDI), which incorporates questions about 11 common psychological and physical symptoms into an index score reflecting the number of symptoms, their frequency, and the degree of associated distress. The original MSAS instrument has been well-validated—and has been used successfully in seriously ill patients both with and without cancer.²⁹ The MSAS-GDI has demonstrated good internal consistency (Cronbach $\alpha = 0.94$ in a sample of 75 patients with cancer³⁰) and criterion validity (Pearson’s correlation $r = 0.79$ with the RAND distress scale³¹). The F-MSAS GDI has demonstrated good internal consistency (Cronbach $\alpha = 0.82$ in a sample of 103 family respondents²⁸).

Analysis

We analyzed all data using SPSS (© 2001 SPSS, Inc., version 11.0.1, SPSS, Inc., Chicago, IL). We compared the Time 1 and Time 2 data using Student’s *t* tests and Pearson χ^2 analyses. We calculated odds ratios to determine what additional variables were associated with increased pain or distress. Variables that were significantly different between Times 1 and 2 and/or that were associated with increased pain or distress were included as independent variables into a logistic regression with pain or distress as the dependent variable. For the logistic regression, the dependent variable was dichotomized (comfortable or mild pain or distress versus moderate or severe pain or distress). Dichotomizing pain variables in order to focus on moderate to severe pain (versus none to mild) has become a standard practice used in such studies as SUPPORT¹⁶ because it simplifies analysis, reporting and comparison between studies. Odds ratios and 95% confidence intervals were calculated.

For study question validation we used the Time 2 data. We assessed item discrimination by comparing the raw percentages of responses to

the study question and the F-MSAS question about the presence or absence of pain. To assess criterion-related validity we calculated Pearson's correlation between our study item and the F-MSAS questions about pain and distress, and conducted a simple logistic regression to test the relationship between responses to the study item and the Global Distress Index.

RESULTS

Subjects

The sample contained 340 subjects in Time 1 and 1384 subjects in Time 2. As planned in the sampling strategy, Time 2 contained more minority decedents than Time 1 (18.2% versus 1.2%, $p < 0.001$). The rate of hospice enrollment increased from 44.4% to 65.1% ($p < 0.001$) from Time 1 to Time 2. Other characteristics of both

decedents and family respondents in the two Times are reported in Table 1.

Study characteristics and nonrespondents

As noted previously, experience gained in locating and recruiting eligible respondents during Time 1 improved respondent location and recruitment during Time 2. The percent of eligible respondents who were identified and completed interviews during Time 1 was 34.9% (340 interviews per 974 death certificates sampled) compared with 45.4% in Time 2 (1384 interviews per 3048 death certificates sampled). To check whether improvements in case finding and recruitment created systematic differences between the two samples, we examined the death certificate data we had for decedents whose respondents were not located or declined to participate (i.e., nonrespondents). The differences between Time 1 and Time 2 nonrespondents' gender (55.6

TABLE 1. DECEDENT AND RESPONDENT (FAMILY CAREGIVER) CHARACTERISTICS, TIME 1 VERSUS TIME 2, OREGON 1996–2002

	Time 1: 1996–1997 n = 340	Time 2: 2000–2002 n = 1384
	Decedent characteristics	
Gender (% female)	51.5	57.4
Age (median in years)	81	81
Minority (%)**a	1.2	18.2 [†]
Location of death**		
Home	45.0	48.6
Nursing Home	43.8	33.5
Other	11.2	18.0
Enrolled in Hospice (%)**	44.4	65.1
Cause of Death (%)		
Cancer	32.6	37.4
Heart disease	17.6	15.5
Cerebrovascular disease	7.6	8
Pulmonary disease	6.8	9.6
Other	35.4	29.5
	Respondent characteristics	
Gender (% Female)	71.2	70.8
Age (Median)*	60.5	59
Relationship to decedent**		
Daughter/stepdaughter	26.2	30.5
Wife	27.9	19.4
Son/stepson	14.4	15.7
Husband	9.1	9.1
Daughter-in-law	5.0	6.1
Other	17.4	19.2
Involvement in Care/(%)**		
Very involved	93.8	94.7
Somewhat involved	6.2	5.3

* $p < 0.05$.

** $p < 0.001$.

^aRacial/ethnic minorities were intentionally oversampled.

versus 57.6% female) and place of death (44.7 versus 48.6% died at home as opposed to nursing home or other) were nonsignificant, while differences in mean age (78.9 versus 76.9, $p \leq 0.05$), and mean years of education (11.8 versus 11.3 years, $p \leq 0.05$) while statistically significant, were in fact quite small. Two differences that were not small were the proportion of decedents who were racial or ethnic minorities (2.2% versus 31.7%, $p < 0.001$, attributable to intentional oversampling), or who died of cancer (28.1% versus 34.3%, $p \leq 0.05$).

Level of comfort in the last week of life

In Time 1, 30.8% of respondents reported that the decedent experienced moderate or severe pain or distress during the last week of life, compared to 48.0% in Time 2 (Pearson $\chi^2 = 31.5$, $df = 1$, $p < 0.001$). Figure 1 shows the breakdown in responses, with a lower proportion of Time 2 respondents reporting that decedents were comfortable, and a higher proportion reporting moderate or severe pain or distress. Calculating odds

ratios for each variable independently, decedents were more likely to be reported to be in greater pain or distress if they died during Time 2, were female, were younger, died of cancer, died at home or were enrolled in hospice. The first column in Table 2 shows the odds ratios and statistical significance calculated for each variable independently.

Logistic regression

In order to control for differences between the two samples and other predictors of increased pain or distress, we performed a multiple logistic regression. with the results reported in the second column of Table 2. The primary independent variable was Time (1 versus 2) and the dependent variable was the study question dichotomized as comfortable or mild pain or distress vs. moderate or severe pain or distress. Variables were included in the equation as covariates if they differed significantly between the two samples (nonwhite race, respondent was spouse, respondent very involved), independently predicted

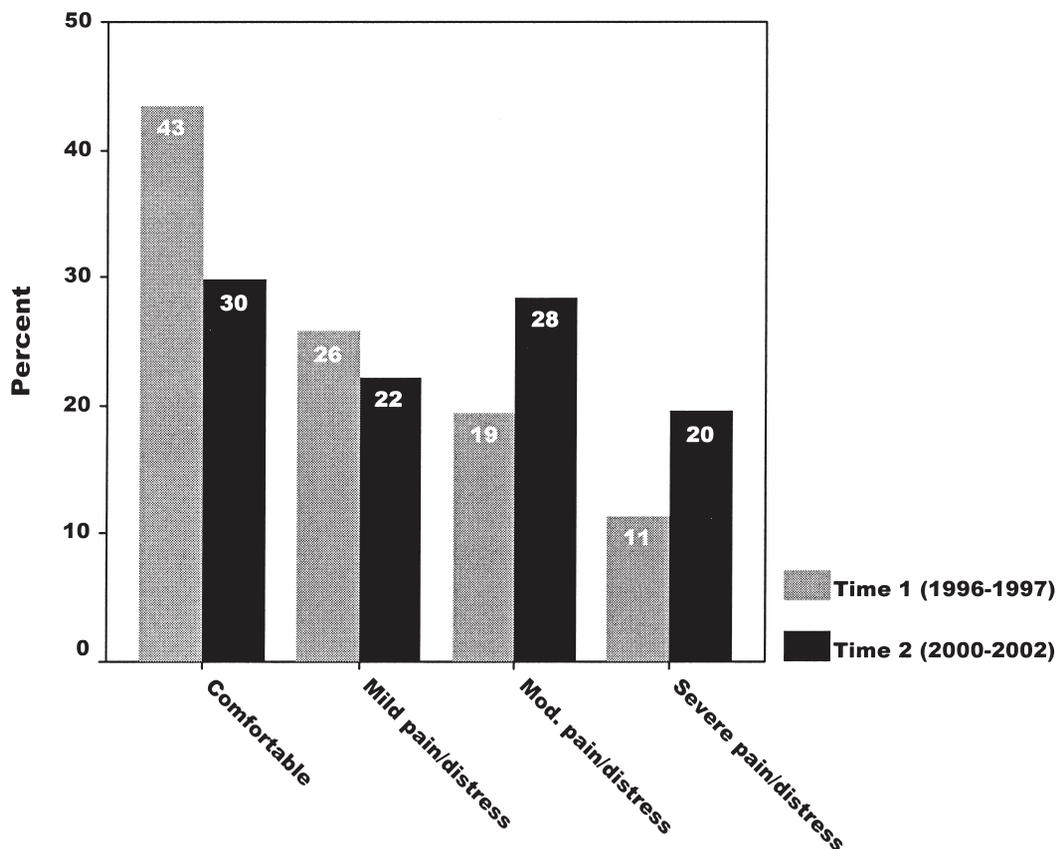


FIG. 1. Level of comfort in the last week of life: Time 1 versus Time 2.

TABLE 2. PREDICTORS OF PAIN OR DISTRESS BEING REPORTED AS "MODERATE OR SEVERE" VERSUS "NONE OR MILD"

	<i>Independent odds</i>				<i>Logistic regression odds</i>			
	<i>Sig (p)</i>	<i>Odds ratio</i>	<i>95% CI</i>		<i>Sig (p)</i>	<i>Odds ratio</i>	<i>95% CI</i>	
Time 2 (vs. Time 1)	0.000	2.066	1.598	2.67	0.000	2.090	1.594	2.745
Decedent female	0.005	1.322	1.613	1.087	0.034	1.263	1.567	1.018
Decedent age in years ^a	0.000	0.978	0.971	0.986	0.000	0.980	0.971	0.989
Respondent age in years ^{a,b}	0.044	0.992	0.985	1.000	—	—	—	—
Died at home (vs. nursing home or other location)	0.005	1.325	1.089	1.612	0.915	1.013	0.804	1.275
Cause of death was cancer (vs. other)	0.001	1.434	1.170	1.758	0.762	1.039	0.812	1.329
Hospice	0.000	1.497	1.221	1.834	0.195	1.171	0.922	1.487
Nonwhite (vs. white)	0.146	1.225	0.935	1.613	0.638	1.072	0.803	1.431
Respondent spouse (vs. other)	0.107	1.192	0.963	1.476	0.637	0.924	0.735	1.207
Respondent very (vs. somewhat) involved caregiver	0.265	1.225	0.790	1.899	0.502	1.168	0.742	1.838

^aContinuous variables.

^bRespondent age in years was not included in the regression model because it correlated so strongly with decedent age.

greater pain or distress (decedent female, decedent age, cause of death was cancer, died at home), or did both (hospice). Table 2 shows the statistical significance and odds ratios of variables in the regression equation. We also performed a multinomial logistic regression without dichotomizing the study question. The results were not appreciably different, however they were much harder to comprehend because each of the four categories was compared to the other three. After controlling for differences between the two samples and other predictors of increased pain or distress, decedents in Time 2 remained approximately twice as likely to be reported to be in moderate or severe pain or distress during the last week of their lives (Time 2 versus Time 1, odds ratio [OR] 2.09, 95% confidence interval [CI] 1.59–2.74). The model itself was significant, explaining 5.9% of the variance in pain or distress (Nagelkerke $R^2 = 0.059$, $\chi^2 = 73.1$, $df = 9$, $p < 0.001$). The only other variables that were significantly associated with greater reported pain or distress were being female (OR 1.26, 95% CI 1.01–1.56), and being younger (for each 1-year decrease in decedent age, the likelihood of moderate or severe pain or distress increased by 2%, 95% CI 0.029–0.011). Decedent age accounted for the predictive value of cancer diagnosis, which accounted for the predictive value of hospice enrollment, which accounted for the predictive value of death at home.

Race/ethnicity

While the percent of minority decedents was much higher in Time 2 because of deliberate oversampling, decedents who were members of racial or ethnic minorities were not statistically significantly more likely than whites to be reported in moderate or severe pain or distress (OR 1.23, 95% CI 0.94–1.61). In the logistic regression, decedent race/ethnicity also was not associated with greater pain or distress (OR 0.934, 95% CI 0.70–1.25), and so the differences in reported pain or distress between Time 1 and Time 2 could not be explained by race.

Question item validation

For the Time 2 respondents, correlations between the study question and the two F-MSAS items and F-MSAS GDI were examined. Specifically, the study question demonstrated excellent discrimination: respondents who reported that decedents were "comfortable" in the study question also reported them to be pain free 77.6% of the time, whereas respondents who reported that decedents had at least mild pain or distress reported them to be pain free 23% of the time ($\chi^2 = 260.2$, 1 degree of freedom, $p < 0.001$). Correspondingly, a dichotomized response to our study question also correlated appropriately with the MSAS item that assessed distress due to pain ($R = 0.510$, $p < 0.01$ [one-tailed]). It also corre-

lated well with the Global Distress Index, with the odds of moderate to severe pain increasing by 4.4 times for each point increase in the Global Distress Index (95% CI 3.523–5.490, $p < 0.001$).

DISCUSSION

The frequency of family reports of moderate or severe pain or distress in Oregon decedents increased—from 30.8% in 1996–1997 to 48% in 1999–2002. To illustrate the magnitude of this increase, consider that 29,909 people died in community-based settings in Oregon during Time 2. An increase from 30.8% to 48% represents the increased suffering of over 5,000 additional decedents and families. Higher levels of pain have profound effects on seriously ill patients and are associated with greater functional impairment,³² greater depression, anxiety and suicidal ideation,³³ and worsening cognition.³⁴ They likewise have intense effects on family caregivers, who are at least as distressed by patients' pain as the patients themselves.³⁵

How are we to understand this finding? First, we must be confident that it does not simply reflect differences between the samples that are artifacts of the methods—particularly in sampling and case-finding/recruitment. We identified meaningful differences between the Time 1 and Time 2 sample decedents (percent minority, percent dying in nursing homes versus other—foster care/assisted living/inpatient hospice, percent enrolled in hospice, percent dying of cancer), respondents (relationship to decedent and involvement in decision-making), and non-respondents (percent minority and percent dying of cancer).

The increased number of racial and ethnic minorities in the Time 2 sample resulted from intentional oversampling, and neither race, cancer, nor any of the other differences explained the differences in pain or distress between the two time periods. The increase in the percent of patients enrolled in hospice and the increased proportion of subjects dying in assisted living, inpatient hospice, and foster care homes simply mirror trends in health care utilization and delivery in Oregon.³⁶ The differences in respondent characteristics (a higher proportion of adult child caregivers with proportionately fewer spouses and more shared caregiving) are almost certainly the result of intentionally improved and more persistent

case finding for Time 2. Therefore, the Time 2 sample includes a higher proportion of "hard to find" respondents. As an example, cohabitating spouses were the easiest to find, whereas adult daughters with different last names were more difficult.

All the measured differences have been adjusted for using logistic regression, but what about unmeasured differences between the samples? Comparing the nonrespondents in Times 1 and 2 provides some reassurance that differences in case finding and recruitment did not significantly bias the two samples. As long as these differences are not the result of a systematic bias introduced by the study methods, unmeasured differences are acceptable because they reflect actual changes in the population, society, and health care that would explain the higher reported pain or distress found in Time 2.

What unmeasured differences in society and health care might explain the higher reported pain or distress found in Time 2? Barriers to effective control of pain are typically divided into patient, family, and system factors. Of these three, patient factors seem the least likely to have changed significantly. No data suggest that illnesses are becoming more painful or distressing during the last week of life, however it is possible that patients' willingness to report pain may have increased, particularly if they believed that pain relief was available.

Similarly, family members may have been more willing to report decedents' pain or distress or perhaps may have perceived it differently in the second time period. A family caregiver's perception of a patient's pain is influenced by the nature of the pain, its duration, and the patient's prognosis. In addition, the caregiver's own pain experience, culture, relationship to the patient, and understanding of the pain, as well as how they interpret the pain's meaning, affect his or her perception.³⁷ Even if patients' pain or distress were unchanged between Times 1 and 2, that family caregivers perceived them to be greater is important, because observing pain in a loved one can be an overwhelming experience that adds to the already heavy burden of caregiving.³⁷ On the other hand, increased reporting of pain or distress could be seen as encouraging if it reflects increased willingness of patients, families, and professional caregivers to acknowledge the presence of pain or distress, to pay greater attention

to its management, or to be dissatisfied when it is inadequately managed.

In trying to understand why families' perceptions of pain or distress and reporting behavior might have changed over the study period, it is helpful to consider Oregon's social and political context. Figure 2 shows our findings in the context of widely publicized events in Oregon before and during data collection. By approving the 1994 Death with Dignity Act, voters made Oregon the only U.S. state to legalize physician-assisted suicide (PAS). The legalization of PAS has been accompanied by extensive local and national media coverage and publicity campaigns funded by stakeholders on both sides. Although legalization of PAS has been the focus, end-of-life care and pain management have received considerable attention. Both proponents and opponents of the legislation agree that excellent end-of-life care is important. Concern for a "chilling effect" on doctors prescribing medication for pain relief in terminally ill patients was central to the 2000 Pain Relief Promotion Act's (a bill that would have made the use of controlled substances for PAS il-

legal) failure to pass the U.S. Senate. A number of other well-publicized events in Oregon may also have affected both family expectations for pain management and professional practice patterns.

In attracting consistent attention and publicity to end-of-life care, PAS, and these other events may have created a "media effect" that has affected the way Oregonians experience or report pain or distress in dying family members. The effects of the media on personal and public health have been increasingly studied over the past decade.³⁸ Media effects have been shown to influence health-related behaviors (e.g., Camel cigarettes' popularity among adolescents increased from 0.5% to 32% in a 3-year period since the beginning of the "Joe Camel" advertising campaign [RJ Reynolds Tobacco Company, Winston-Salem, NC]³⁹), health care decisions (e.g., screening mammography rates increased after Betty Ford's and Happy Rockefeller's disclosure of their breast cancers^{40,41}), and have even been implicated in some diseases (e.g., increased rates of anorexia nervosa in 15 through 24-year-olds mirror times

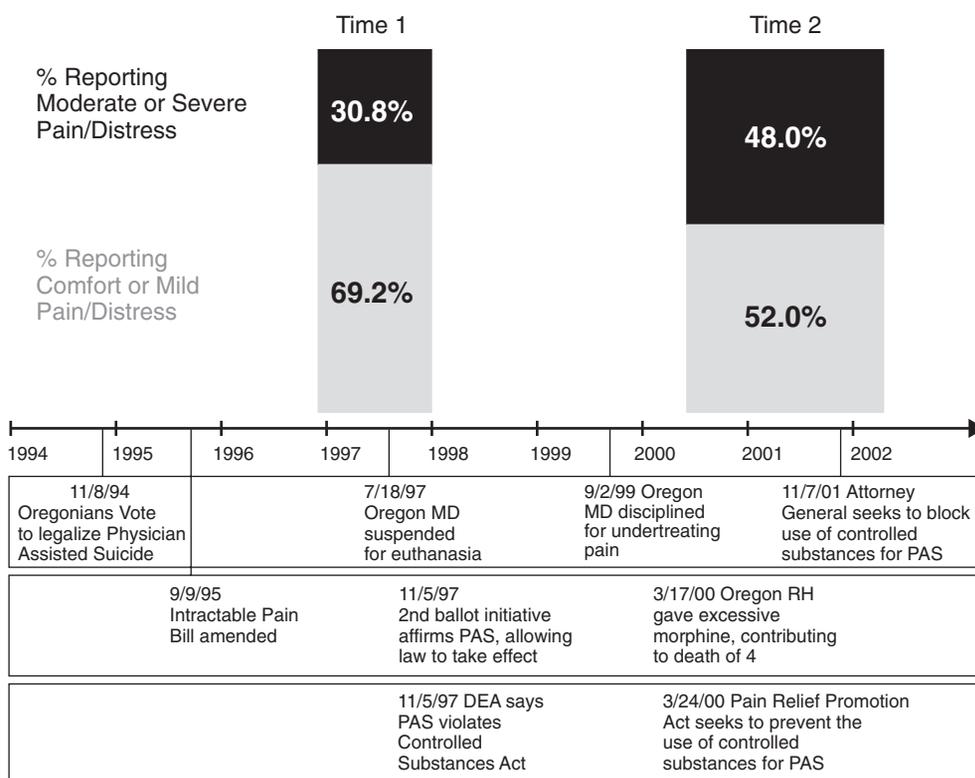


FIG. 2. Comparison of family reports of pain or distress during Time 1 and Time 2 in relation to a timeline of concurrent publicized events.

in history in which the media has portrayed thinner models^{42,43}). Although media effects are usually thought to be strongest in children and young people whose beliefs are developing,³⁸ it is plausible that a media effect associated with the 1994 and 1997 PAS ballot measures and their publicity campaigns could influence how Oregonians perceive, interpret, evaluate and treat pain or distress in dying family members. Likewise, health care providers are susceptible to media effects⁴⁴ and may have changed the way they approach pain in certain patient populations, as is suggested by Oregon physicians' attempts to learn more about the use of pain medicines in dying patients.²¹

Last, we return to the original question of whether efforts to improve the care of the dying are having an effect on pain management. Could changes in the health care system account for the increased family caregivers' reports of pain or distress? A more worrisome interpretation of our findings would be to suggest that palliative care in the final week of life has worsened in Oregon. For most patients and families, the final week of life is a time of rapid changes and emotional intensity.⁴⁵ Even previously well-cared for and well-compensated patients' last days are commonly afflicted by conditions that are distressing and difficult to manage, such as acute dyspnea, delirium, seizures, incontinence, myoclonus, bleeding, and the "death rattle."⁴⁵ A responsive, flexible system that can divert considerable resources to patients and families in distress is needed to skillfully manage this time. It takes time and specially trained personnel to "stay on top of" evolving symptoms, teach family caregivers what they need to know in order to feel comfortable, and adequately support the distinct psychosocial and spiritual needs of patients and individual family members.

Despite the national attention received by end-of-life care, have greater resources actually been apportioned to provide better care? In Oregon, there is evidence that these resources have been stretched more thinly. Medicare patients in Oregon have among the lowest reimbursement in the United States during the last 6 months of life and have fallen significantly during the study period.⁴⁶ In 1994–1995 the average price-adjusted Medicare reimbursements for hospital care during the last 6 months of life of a Portland resident was \$6,793.⁴⁷ In 1999, this amount had fallen to \$4,499, and a similar trend is seen in other Ore-

gon cities including Salem, which had the lowest reimbursement rate in the United States (\$3,767).⁴⁶ This suggests that end-of-life care in Oregon was already resource lean and has become more so. In nursing homes, the amount of money that the average nursing facility loses per Medicaid patient per day has tripled during the study period.⁴⁸ Furthermore, the nursing shortage means that the skilled practitioners needed to manage dying patients in homes and nursing facilities are in short supply.⁴⁹ Although nurses aides spend the most time with each patient, lack of support and high turnover rates⁴⁹ impede them from acquiring adequate training and experience in the care of dying patients.

Comparing 1996 to 2002, the number of Oregonians dying while enrolled in hospice has increased from approximately 8000 to 13,000 while the median length of stay is a week shorter and the mean number of nursing visits per patient has decreased from 16 to 12.7 (unpublished data).⁵⁰ The negative impact of overstressing nursing resources on pain management should not be underestimated because of the amount of time needed for nurses to assess patients, contact physicians for order changes, and reevaluate patients to ensure that therapy is adequate. A 1995 study of Oregon nursing home residents found that lack of assessment and reevaluation of the effectiveness of treatment for pain were the main contributors to inadequate pain treatment.⁵⁰ Finally, although Oregon is consistently among the highest purchasers of opioid per capita and has consistently increased its purchasing over the study period,^{51,52} the state's largest academic medical center recently found that these increases were not going to patients dying in that hospital.⁵³

It may be that at the same time expectations have been raised, resources available to patients have been stretched more thinly, limiting families' and professional caregivers' abilities to respond quickly and flexibly to the rapidly changing events of the final week of life. Alternatively, it may be that the family caregivers' reports reflect their own dissatisfaction with the care and support they and the patient received (and their own resulting distress), although many patients report satisfaction with pain control despite pain levels that seem quite high.⁵⁴

This study has limitations that are important to note, in addition to those already mentioned. Foremost is that family caregivers, not decedents,

were asked to report on decedents' pain or distress. However, family perceptions have validity in their own right, so the question of the validity of family reports about decedents' experiences must be balanced by the question of the feasibility of asking decedents to report on their last days and hours of life. Furthermore, although this study relies on a single question, the degree to which this question correlates with other items assessing pain or distress and the global distress index is reassuring. The validation measures suggest that the study question does discriminate between pain-free and painful states and demonstrates concurrent criterion validity with the F-MSAS distress due to pain item and FMSAS-GDI. The moderately strong correlations are appropriate given that questions posed did not ask for exactly the same information using exactly the same language. It is also possible that differences between the questions in each instrument that preceded the study question changed the way respondents answered the study question. However, the previously referenced study of 103 hospitalized Oregon decedents used an instrument identical to the Time 1 instrument and also demonstrated a similarly increased (54%) prevalence of family reported moderate to severe pain and distress.²⁸ This supports the notion that the prevalence has increased and is not an artifact of the different instruments. Finally, Oregon differs significantly from other parts of the country demographically and in key end-of-life care measures and Oregon data should not be generalized to some regions of the United States.

Despite its limitations, this study demonstrates that pain or distress are still substantial problems for dying patients in Oregon, despite multiple efforts to improve end-of-life care. End-of-life care has not been "fixed" and there is plenty of room for improvement, particularly in the final week of life. Clinicians, health care organizations, and policy makers must continue to improve the quality and availability of hospice and palliative care services if dying patients are to get the care they need and deserve. For future research that aims to evaluate the quality of end-of-life care in large populations, it will be important to investigate what effects the media and publicized events have on families' and patients' expectations, perceptions, and evaluations of their care. Finally, more research is needed to investigate the impact of nursing shortages on care in the final week of life.

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