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Joel C. Cantor

*Rutgers University - New Brunswick/Piscataway*

Jan Blustein

*New York University*

Matthew J. Carlson

*Portland State University, carlsonm@pdx.edu*

David A. Gould

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# Next-of-Kin Perceptions of Physician Responsiveness to Symptoms of Hospitalized Patients Near Death

JOEL C. CANTOR, Sc.D.<sup>1</sup>, JAN BLUSTEIN, M.D., Ph.D.,<sup>2</sup> MATHEW J. CARLSON, Ph.D.,<sup>3</sup>  
and DAVID A. GOULD, Ph.D.<sup>4</sup>

## ABSTRACT

Many different medical providers visit critically ill patients during a hospitalization, and patients and family members may not feel any physician is truly in charge of care. This study explores whether perceiving that a physician was clearly in charge is associated with reports by surviving next of kin about the responsiveness of physicians to symptoms in hospitalized patients near the end of life. We conducted telephone interviews with surviving next of kin of adult patients ( $n = 1107$ ) who died in one of five New York City teaching hospitals between April 1998 and June 1999 after a minimum 3-day inpatient stay. Next-of-kin ratings of whether physicians did "all they could" all or most of the time in response to patient pain, dyspnea, and affective distress (confusion, depression or emotional distress) were compared by whether the next of kin reported one or more physicians "clearly in charge" of care, adjusting for patient and next-of-kin characteristics. More than 80% of patients were reported to have experienced often serious pain, dyspnea, or affective distress. Physicians were rated as responsive to pain by 79.1% of respondents, to dyspnea by 84.9%, and to affective distress by 66.6%. Ratings of physician responsiveness to pain ( $p = 0.001$ ) and affective distress ( $p = 0.001$ ) were significantly lower among patients for whom no physician was seen as clearly in charge of care. This finding is consistent with the view that ensuring that a physician coordinates the care of seriously ill, hospitalized patients may improve symptom management. Further research is warranted to establish causality and identify optimal models of care.

## INTRODUCTION

FOR PATIENTS NEAR THE END OF LIFE, palliation of symptoms is of paramount importance. Yet studies suggest that those spending their final days in hospitals often die with symptoms unchecked. For example, in the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT), half of pa-

tients dying in acute care hospitals had moderate to severe pain at least half of the time during their final days of life.<sup>1</sup> Other studies confirm that the failure to control symptoms in hospitalized dying patients is widespread.<sup>2,3</sup>

This failure is significant because more than one half of deaths in the United States occur in hospitals.<sup>4</sup> Hospitals are complex institutions in which providers with different roles and per-

<sup>1</sup>Center for State Health Policy, Rutgers, the State University of New Jersey, New Brunswick, New Jersey.

<sup>2</sup>Wagner Graduate School, New York University, New York, New York.

<sup>3</sup>Department of Sociology, Portland State University, and Oregon Health & Science University, Portland, Oregon.

<sup>4</sup>United Hospital Fund, New York, New York.

spectives share responsibility for patient care. Sometimes the boundaries of responsibility and accountability for patient care are unclear or even contentious.<sup>5</sup> These ambiguities are often intensified in the care of seriously ill patients,<sup>6</sup> in intensive care settings,<sup>7,8</sup> and in academic medical centers.<sup>5</sup> Moreover, during hospitalization, providers who have not previously been involved in the care of the patient—including subspecialists, consultants, and hospitalists—sometimes take on central roles in patient care. Some have suggested that this unfamiliarity breeds discontinuity, which in turn undermines the quality of hospital care.<sup>9</sup>

How might ambiguities and discontinuities of responsibility be related to the quality of care that is delivered to hospitalized patients at the end of life? We addressed this question by examining the relationship between next-of-kin reports of whether one or more physicians were “clearly in charge” of patient care and whether the physicians did “all they could” to control symptoms among patients who died in five New York City teaching hospitals.

The perspectives of surviving next of kin are important in their own right and are relevant markers of the quality of care. Next of kin are important participants in and observers of care. Family members often spend a great deal more time in hospitals with patients than do physicians or the hospital staff, and they are frequently present for physician-patient discussions or serve as proxy decision-makers for incompetent patients. Prior studies have shown that surrogates such as family members are moderately accurate raters of symptoms such as pain, although they may over-report symptoms and may be more critical than patients of caregivers.<sup>10-12</sup>

As clinicians strive to improve symptom management in patients near death, it is important to understand the correlates of good outcomes. This knowledge can inform the design of care strategies, such as special palliative care units or palliative care consultation teams, as well as guide the design of future research in this area.

## METHODS

### *Study setting and sample*

The five study hospitals were participants in a program to improve the care of patients near the

end of life sponsored by the United Hospital Fund of New York.<sup>13</sup> The hospitals range from 511 to 1027 beds in service, and have between 35 and 74 medical residents per 100 beds (authors’ tabulations of 1998 New York State Institutional Cost Reports). Two of the study sites are academic health centers affiliated with medical schools.

A probability sample of 2528 patients 18 years of age or older with a minimum stay of 3 days prior to dying between April 1998 and June 1999 was drawn from the hospitals’ computerized records. Patients receiving special palliative care services were oversampled in two of the hospitals. We use statistical controls to address the possibility of bias introduced by the intervention oversample (see Analysis below).

The Institutional Review Boards of the five participating hospitals approved the research reported in this paper. Beginning in November 1998, letters describing the study and stating that responses were voluntary and confidential were mailed no sooner than 6 weeks after death to surviving next of kin listed in hospital records. Interviewing was conducted between December 1998 and November 1999.

### *Study data*

The primary data for the study were collected during computer-assisted telephone interviews with the listed next of kin between 2 and 17 months after the patient’s death. Half of interviews were completed between 5 and 7 months after death and 99% were completed within 12 months after death. Interviews averaged 22 minutes and were conducted by experienced interviewers who had been trained to administer the study questionnaire and to consider the special needs of bereaved and elderly respondents. After obtaining oral informed consent, interviewers asked respondents about perceptions of the patients’ conditions and care during the hospital stay during which the patients died. In addition, data from computerized hospital records on length of stay, expected primary source of payment, admitting diagnosis, and patient age and gender were linked to the data derived from the telephone interviews. Although of potential importance, data on the characteristics of physicians or other care providers were unavailable.

The outcomes examined in this paper are based

on respondent assessments of physicians' level of effort to treat patient symptoms. The respondents were asked about the extent to which patients experienced pain, shortness of breath, and affective distress (confusion, depression or emotional distress). Then, those reporting that the patient experienced symptom(s) were asked for their assessment of the adequacy of physician responsiveness to symptoms. For example, for patients who experienced pain, respondents were asked, "Do you think that the doctors did everything they could to help control (patient's name/relationship) pain . . . all of the time, most of the time, about half of the time, some of the time, or none of the time?" Respondents were asked parallel questions about physicians' efforts to help patients "breathe more easily" and to relieve "confusion, depression or emotional distress."

In a separate series of questions, respondents were asked about the physicians caring for the patients during the hospital stay. First, respondents were asked, ". . . was there one doctor who was clearly in charge of (patient's name/relationship) care, more than one doctor in charge, or no doctor who was clearly in charge of (his/her) care?" Those who reported that there was one or more doctors "clearly in charge" were then asked whether those physicians were ". . . involved in caring for (patient's name/relationship) before that hospital stay?"

Data were also collected to control for factors that might confound the association between respondent reports of whether there was a physician clearly in charge and the physician responsiveness to symptoms. Covariates included respondent and patient demographic and socioeconomic characteristics as well as patient living arrangements and health and disability status prior to admission. Additionally, because prior research has shown respondent expectations to be associated with satisfaction with care, respondents were asked when they first realized that the patient would die.<sup>14,15</sup> Some respondents did not know or refused to answer some survey questions and some data were missing from hospital administrative records. Cases with missing values were excluded from analysis, except for household income in the last year and major diagnostic category where more than 10% of the cases were missing. For these variables, to avoid potential selection bias a "missing" category was included in the analysis.

### Analysis

After tabulating sample characteristics, we examined the association between the reported level of physician efforts to address symptoms and respondent and patient characteristics. We focused on the association of whether there was a physician(s) clearly in charge of patient care and the responsiveness of physicians to symptoms. Respondent and patient covariates that we found to be significantly associated with physician responsiveness in bivariate  $\chi^2$  tests at a level of  $p < 0.05$  or lower were controlled for in estimating adjusted odds ratios in logistic regression models. In addition, to help ensure that estimates were unbiased, the regression models also controlled for the sampling strata (i.e., hospital and palliative care program participation). As well, unadjusted odds ratios for physician-in-charge variables were computed for comparison to the adjusted ratios for these variables.

## RESULTS

Of the initial 2528 cases, 209 (8.3%) hospital records did not have adequate contact information for a surviving next of kin and 61 (2.4%) had contact information, but the named person reported having had no interaction with the hospital staff caring for the patient. These cases were considered ineligible for the study. Of the remaining 2258 cases, 412 (18.2%) could not be located using the contact information provided; 176 (7.8%) could not be reached after multiple attempts, 58 (2.6%) were unable to participate because of incapacitation or language barrier, and 350 (15.5%) refused to participate. Interviews were conducted with the remaining 1271 next of kin, yielding a response rate of 56.3%. While less than ideal, this rate is comparable to studies of patient experiences and satisfaction reported in the literature.<sup>16-18</sup>

Response rates varied among the five hospitals from 46.3% to 63.3% ( $p < 0.001$ ); and were lower for patients with an expected payment source of Medicaid or uninsured (47.0%) compared to Medicare (57.2%) or privately insurance (64.9%;  $p = 0.001$ ) and for women patients (54.3%) compared to men (58.5%;  $p = 0.044$ ). Response rates did not vary significantly by patient age, major diagnostic category, or length of stay. The analysis presented here is limited to 1107 (87.1%) cases

rated by interviewers as knowledgeable on "all" or "most" questions on a four-point scale (compared to "some" or "very few or none" of the questions).

Table 1 describes the analysis sample. With respect to the main independent variables of interest in this study, no doctor was seen as clearly in charge in nearly 20% of cases, and approximately half of the remaining respondents reported that although a physician(s) was in charge, he or she had no relationship to the patient prior to the final hospitalization.

Respondents were predominantly women and predominantly nonelderly. Forty percent reported that they had no more than a high school education, and the modal relationships to the patient were child and spouse/partner. More than half of all respondents had not expected that the patient would die during the hospital stay until near the very end. However, a sizable minority, nearly a quarter, said that they realized that the patient would die prior to or just after admission.

As shown in the second part of Table 1, study patients were quite old and sick, with high proportions reported in fair or poor health status or living in a nursing home two months prior to admission. Approximately half of the patients were women, approximately half were non-white, and most reportedly spoke English "very well." On average, the patients had lower educational attainment than their next of kin ( $p < 0.001$ ) did, with only one third having more than a high school degree. Data from the two thirds of respondents who reported patient income show that the patients were typically of modest means. Medicare was the predominant expected primary payer, followed by private coverage and Medicaid or no coverage. Finally, the patient population had a diversity of admitting diagnoses, and a large proportion had lengthy hospital stays. Reports of having one or more physician(s) "clearly in charge" varied by respondent and patient socioeconomic circumstances, patient living situation prior to admission and diagnosis; but not by other sample characteristics (data not shown).

As summarized in Table 2, more than 8 in 10 patients were reported to have experienced pain, dyspnea, or affective distress (confusion, depression, or emotional distress) during their final hospitalization. Respondent reports of physician responsiveness varied by symptom. Physician responsiveness was rated highly (defined as reports

of physicians doing "all that they could" to address symptoms either "all of the time" or "most of the time") in 79.1% of pain cases, 84.9% of dyspnea cases, and 66.6% of cases with affective distress.

Physician responsiveness was rated higher when a physician was seen as clearly in charge, although this difference was not significant for dyspnea (Table 3). In the case of pain, physician responsiveness ratings were higher when the physician(s) in charge had a relationship to the patient prior to the hospitalization compared to when no prior relationship was reported ( $p = 0.043$ ).

Several respondent characteristics were also associated with ratings of physician responsiveness. Older respondents tended to rate physicians as being more responsive, as did respondents who had anticipated the patient's death prior to the admission. Few patient factors were associated with ratings of physician responsiveness. Notably, only prior health status was consistently linked with responsiveness. Higher physician responsiveness to symptoms associated with poorer patient health. Consistent with the health status finding, physician responsiveness ratings were higher for patients who previously lived in an institution such as a nursing home, although this was significant only for dyspnea. Other patient characteristics (race/ethnicity, education, English-speaking ability, household income, expected primary payer class) as well as expected payer, diagnosis, length of stay and hospital were not consistently associated with physician responsiveness to symptoms.

Logistic regression models are consistent with the results shown above and demonstrate that the association between the physician-in-charge variable and symptom management are not altered when controls for covariates are added. As shown in Table 4, reports of having a physician clearly in charge was associated with a greater odds of a high rating of physician effort to address pain and affective distress compared to having no physician in charge in both unadjusted and adjusted models. In the case of pain, significantly higher physician responsiveness was found for patients with a physician(s) in charge who cared for them prior to the hospitalization compared patients with a physician(s) in charge but without a prior relationship in the unadjusted model (odds ratio [OR] = 1.6; confidence interval [CI] = 1.1, 2.5) although this association is of borderline

TABLE 1. SAMPLE CHARACTERISTICS

	%
Physician "clearly in charge" ( <i>n</i> = 1,093)	
None	18.5
Yes, without prior relationship	39.1
Yes, with prior relationship	42.5
Respondent	
Women ( <i>n</i> = 1107)	70.1
Age group ( <i>n</i> = 1085)	
19–39 years	17.8
40–49	23.7
50–64	35.6
65–74	14.9
75 or older	8.0
Education ( <i>n</i> = 1102)	
Less than high school	12.3
High school graduate	27.6
Some college	19.2
College graduate	40.9
Lived with patient ( <i>n</i> = 1104)	44.5
Relationship to patient ( <i>n</i> = 1107)	
Spouse/partner	26.1
Parent	4.2
Child	44.2
Sibling	9.6
Other	16.0
When death was first expected ( <i>n</i> = 1082)	
Prior to admission	9.8
Just after admission	14.3
About half way through hospital stay	22.9
Not expected or not sure	53.0
Patient	
Women ( <i>n</i> = 1107)	50.1
Age group, years ( <i>n</i> = 1107)	
50 and under	15.8
51–64	18.8
65–74	19.2
75–84	26.9
85 or older	19.3
Race/ethnicity ( <i>n</i> = 1088)	
White, non-Hispanic	51.5
Black, non-Hispanic	27.2
Hispanic	16.5
Other	4.9
Education ( <i>n</i> = 1036)	
Less than high school	33.4
High school graduate	34.3
Some college	12.0
College graduate	20.4
Spoke English "very well" ( <i>n</i> = 1006)	86.7
Health status—2 months prior to admission ( <i>n</i> = 1082)	
Excellent, good, or very good	29.9
Fair	30.0
Poor	40.1
Lived in institution—2 months prior to admission ( <i>n</i> = 1097)	15.9
Household income last year ( <i>n</i> = 732)	
Under \$15,000	41.9
\$15,000–\$49,999	35.9
\$50,000 or more	22.1
Expected primary payer class ( <i>n</i> = 1063)	
Medicare	61.6
Medicaid, self-pay, or charity care	15.5
Private coverage	22.9

*(continued)*

TABLE 1. SAMPLE CHARACTERISTICS (CONT'D)

	%
Major diagnostic category ( <i>n</i> = 947)	
Neoplasms	19.7
Circulatory system	20.6
Respiratory system	17.3
Digestive system	9.7
Infectious/parasitic conditions	12.0
Other	20.6
Length of stay, days ( <i>n</i> = 1107)	
3-5	14.8
6-9	21.6
10-15	22.0
16-27	20.1
28-more	21.6
Hospital ( <i>n</i> = 1107)	
A	18.3
B	18.8
C	21.3
D	21.3
E	20.2

significance in the adjusted model (OR = 1.6; CI = 1.0, 2.5). Having a prior relationship did not have a significant association with physician responsiveness for the other two symptoms (data not shown).

## DISCUSSION

Consistent with prior studies of hospitalized patients near the end of life, respondents in our study reported high levels of symptoms in a series of patients who died in the study hospitals.<sup>1-3</sup>

More than 80% of patients reportedly experienced pain, dyspnea, or affective distress. Moreover, next-of-kin ratings of the adequacy of physician efforts to address the symptoms were not consistently positive, with between 15.2% and 33.5% reporting that physicians failed to do "all they could" most of the time to address symptoms, depending on the symptom addressed.

Nearly 1 in 5 respondents reported that no physician was clearly in charge of patient care, and these respondents rated physician responsiveness to affective distress and pain substantially lower than respondents who reported that

TABLE 2. NEXT-OF-KIN REPORTED SYMPTOMS AND DEGREE TO WHICH PHYSICIANS WERE PERCEIVED TO DO "ALL THEY COULD" TO ADDRESS SYMPTOMS

	<i>Symptom</i>		
	<i>Pain</i>	<i>Dyspnea</i>	<i>Distress<sup>a</sup></i>
Symptom prevalence			
%	82.4	85.7	80.9
<i>n</i>	934	1023	920
Of patients with the symptom, reports of "doctors did all they could" to address symptoms, % distribution			
All of the time	46.4	55.9	37.5
Most of the time	32.7	29.0	29.1
About half of the time	6.6	4.9	8.4
Some of the time	10.9	7.3	14.5
None of the time	3.4	3.0	10.6
<i>n</i>	731	838	667

<sup>a</sup>Confusion, depression or emotional distress.

TABLE 3. PERCENT OF NEXT-OF-KIN REPORTING THAT PHYSICIANS DID "ALL THEY COULD" TO ADDRESS SYMPTOMS ALL OR MOST OF THE TIME BY SAMPLE CHARACTERISTICS

Sample characteristics	Symptom <sup>a</sup>					
	Pain (n = 731)		Dyspnea (n = 838)		Distress <sup>b</sup> (n = 667)	
	%	p	%	p	%	p
Total	79.1	—	84.8	—	66.6	—
Physician "clearly in charge"		0.001		0.118		0.001
None	66.4		79.6		50.4	
Yes, without prior relationship	78.2		86.1		68.1	
Yes, with prior relationship	84.7		86.3		71.7	
Respondent						
Gender		0.606		0.522		0.877
Women	80.3		83.6		66.4	
Men	78.6		85.4		67.0	
Age group		0.025		0.053		0.003
19–39 years	72.1		78.3		56.7	
40–49	75.0		83.9		62.2	
50–64	84.6		88.2		73.8	
65–74	81.6		88.4		69.2	
75 or older	81.5		86.2		79.5	
Education		0.250		0.120		0.051
Less than high school	77.4		77.1		71.1	
High school graduate	74.3		84.1		72.2	
Some college	81.8		86.4		68.7	
College graduate	81.1		86.7		60.7	
Lived with patient		0.562		0.011		0.907
Yes	79.8		81.1		66.3	
No	78.0		87.5		66.8	
Relationship to patient		0.236		0.314		0.005
Spouse/partner	83.0		87.5		66.9	
Parent	79.4		80.0		80.7	
Child	75.5		82.8		60.0	
Sibling	84.6		90.2		79.3	
Other	79.3		84.5		72.6	
When death was first expected		0.002		0.001		0.001
Prior to admission	90.5		89.3		80.0	
Just after admission	87.1		95.1		83.3	
About half way through hospital stay	78.7		85.9		66.9	
Not expected or not sure	74.2		80.5		59.3	
Patient						
Gender		0.008		0.078		0.662
Women	75.1		82.7		67.4	
Men	83.0		87.1		65.8	
Age group, years		0.050		0.716		0.746
50 and under	83.2		83.2		67.2	
51–64	75.2		82.0		68.3	
65–74	75.5		86.1		62.6	
75–84	76.7		85.6		69.2	
85 or older	87.6		86.9		63.9	
Race/ethnicity		0.217		0.012		0.289
White, non-Hispanic	80.9		88.5		67.1	
Black, non-Hispanic	80.1		84.1		70.0	
Hispanic	73.3		78.8		63.1	
Other	71.8		75.7		53.6	
Education		0.350		0.916		0.029
Less than high school	76.5		84.6		69.2	
High school graduate	77.4		84.7		68.7	
Some college	85.1		84.0		66.7	
College graduate	80.4		86.8		54.2	

(continued)

TABLE 3. PERCENT OF NEXT-OF-KIN REPORTING THAT PHYSICIANS DID "ALL THEY COULD" TO ADDRESS SYMPTOMS ALL OR MOST OF THE TIME BY SAMPLE CHARACTERISTICS (CONT'D)

Sample characteristics	Symptom <sup>a</sup>					
	Pain (n = 731)		Dyspnea (n = 838)		Distress <sup>b</sup> (n = 667)	
	%	p	%	p	%	p
Spoke English "very well"		0.918		0.188		0.264
Yes	80.2		85.9		97.9	
No	80.7		81.0		62.0	
Health status 2 months prior to admission		0.001		0.001		0.002
Excellent, good or very good	72.1		78.5		59.4	
Fair	75.4		83.3		62.6	
Poor	86.9		90.8		73.8	
Lived in institution 2 months prior to admission		0.055		0.006		0.551
Yes	86.1		92.5		69.6	
No	77.8		83.2		66.1	
Household income last year		0.552		0.389		0.417
Under \$15,000	82.3	0.391 <sup>c</sup>	88.2	0.255 <sup>c</sup>	66.7	0.642 <sup>c</sup>
\$15,000-49,999	76.7		82.7		64.8	
\$50,000 or more	79.1		84.2		61.1	
Unknown/refused	78.0		83.8		70.3	
Expected primary payer class		0.894		0.326		0.661
Medicare	79.1		85.5		65.3	
Medicaid, self-pay, or charity care	77.2		80.2		70.0	
Private coverage	78.1		84.7		67.1	
Major diagnostic category		0.264		0.035		0.440
Neoplasms	79.2	0.393 <sup>d</sup>	80.9	0.021 <sup>d</sup>	65.0	0.322 <sup>d</sup>
Circulatory system	77.1		87.9		64.4	
Respiratory system	81.1		83.9		66.3	
Digestive system	77.3		88.1		69.5	
Infectious/parasitic conditions	84.4		93.4		77.3	
Other	72.0		78.1		61.4	
Missing	84.4		86.0		67.0	
Length of stay, days		0.301		0.888		0.800
3 to 5	75.3		83.5		64.8	
6 to 9	82.9		84.0		64.7	
10 to 15	77.6		86.2		68.0	
16 to 27	82.8		86.6		70.4	
28 or more	75.7		83.6		64.5	
Hospital		0.034		0.050		0.615
A	69.7		77.4		60.9	
B	82.8		86.2		67.2	
C	76.5		84.7		65.0	
D	81.5		89.0		69.4	
E	83.1		86.2		69.0	

<sup>a</sup>Sample sizes for individual variables may be less than the totals due to missing values, *p* values are shown with and without missing values for variables with 10% or more missing.

<sup>b</sup>Confusion, depression or emotional distress.

<sup>c</sup>*p* value excluding "unknown/refused" cases, pain (*n* = 495), dyspnea (*n* = 554), affective distress (*n* = 455).

<sup>d</sup>*p* value excluding missing cases, pain (*n* = 616), dyspnea (*n* = 717), affective distress (*n* = 564).

a physician(s) was in charge. This contrast was greatest for affective distress symptoms, only half of respondents reported that physicians did "all they could" all or most of the time to address distress when no physician was seen as in charge, but nearly three fourths reported adequate physi-

cian efforts when a physician was seen as in charge and he/she cared for the patient prior to the hospitalization. Comparable ratings of physician responsiveness to pain were 66.4% with no physician in charge and 84.7% when a physician with a prior relationship was in charge. Smaller

TABLE 4. ODDS RATIOS OF NEXT-OF-KIN REPORTING THAT PHYSICIANS DID "ALL THEY COULD" TO ADDRESS SYMPTOMS ALL OR MOST OF THE TIME

	Odds Ratio (95% Confidence Interval)					
	Pain (n = 684)		Dyspnea (n = 770)		Distress <sup>a</sup> (n = 595)	
	Unadjusted	Adjusted <sup>b</sup>	Unadjusted	Adjusted <sup>b</sup>	Unadjusted	Adjusted <sup>b</sup>
Physician "clearly in charge"						
With prior relationship	3.0 (1.9, 4.9)	3.1 (1.8, 5.1)	1.6 (1.0, 2.7)	1.6 (0.9, 2.7)	2.4 (1.5, 3.8)	2.2 (1.3, 3.6)
Without prior relationship	1.8 (1.1, 2.9)	1.9 (1.2, 3.2)	1.6 (0.9, 2.7)	1.5 (0.8, 2.6)	2.1 (1.3, 3.3)	2.0 (1.2, 3.4)
No physician in charge	1.0 <sup>c</sup>	1.0 <sup>c</sup>	1.0 <sup>c</sup>	1.0 <sup>c</sup>	1.0 <sup>c</sup>	1.0 <sup>c</sup>

<sup>a</sup>Confusion, depression, or emotional distress.

<sup>b</sup>Controls for covariates with independent association with respective symptom (at  $p < 0.05$ ) as shown in Table 3.

<sup>c</sup>Indicates reference category.

Note: Unadjusted and adjusted models estimated by logistic regression. All regressions control for survey sampling strata.

and statistically insignificant differences were observed for management of dyspnea.

Respondents who reported an early expectation of death and those who reported lower prior patient health status were also more likely to report adequate physician responsiveness to symptoms. The effect of continuity in the physician-patient relationship was less evident. Differences in reported symptom responsiveness between physicians without a relationship to the patient prior to the hospital stay and those with a prior relationship were small and generally not statistically significant, except in the case of pain control.

Our findings suggest that it may be important for hospitals to organize services to ensure that each patient is assigned one or more physicians to coordinate care, but ensuring that patients' community-based physicians play that role may not be essential. The finding that expectation of death prior to admission was associated with higher ratings of physician responsiveness underscores the importance of early and effective communication between care providers and family members about the patient's illness and likelihood of survival. We do not have data to address whether family or provider expectations about survival led to greater emphasis on palliative care, although this is a clear possibility.

It is noteworthy that several factors were not generally associated with reports of physician responsiveness to symptoms. Specifically, we did not find that race/ethnicity or indicators of socioeconomic status or insurance coverage were associated with responsiveness. These findings are reassuring and are not consistent with prior

findings of lower quality of care and pain control for poor and minority patients.<sup>19,20</sup> We did, however, find differences in physician symptom responsiveness among the study hospitals in multivariate analysis controlling for patient and next-of-kin characteristics.

Our analysis has several limitations. First, we reported on a retrospective survey of surviving next of kin, which required recall (on average approximately 6 months) and reflected perceptions of individuals without medical training. Prior evidence suggests that compared to patients, surrogate respondents may report more symptoms and be more critical of caregivers, but we have no reason to believe that this evidence suggests a bias in the association between reported physician-patient relationship and reported adequacy of symptom management. Nevertheless, we attempted to control for differences in the subjective judgments among respondents by measuring respondent characteristics that might be correlated with perceptions (for example, age, gender, and educational attainment). We also limited our analysis to cases where interviewers rated responding next of kin as knowledgeable. While further work in this area would be strengthened by incorporating objective measures, we note that family members are uniquely positioned to observe the unfolding course of care and their experiences are important in their own right.

Second, the study is cross sectional and causal inferences must be made with caution. While we have suggested that having a physician in charge led to more satisfactory symptom management, it may have been that better symptom control led to the perception that a physician was in charge.

The issue of causality can be addressed more effectively only through longitudinal or intervention research. Third, we did not describe the organization of care beyond whether a physician was reported to be in charge. The role or responsiveness of nurses or other caregivers who might have been involved in the symptom management, and the characteristics of the physicians providing care such as specialty or level of training. In particular, the growing use of hospitalists is worthy of examination in further research. Finally, our survey was limited to five teaching hospitals in one region. Experiences in other settings might differ from our study facilities, and within these hospitals we cannot rule out the possibility that nonrespondents might have reported differently than respondents.

In conclusion, symptom control and physician responsiveness to symptoms are serious concerns for hospitalized patients near the end of life and their families. Our findings suggest that ensuring that one or more physicians are clearly in charge of care of each patient may be an important step toward improving the quality of care for hospitalized dying patients. Future research on palliative care interventions should examine the potential contribution of a primary, coordinating physician. In the absence of contrary evidence, our study suggests that it is advisable for hospital-based palliative care interventions to encourage a strong role for a coordinating physician.

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### REFERENCES

1. SUPPORT Principal Investigators: 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). *JAMA* 1995;274:1591-1598.
2. Benson JM, Cantor JC, Lynn J, Teno J: A national perspective on dying in America: Does place of death matter? Brief Report. *J Am Geriatr Soc* May 2000; 48:5230-5231.
3. Hearn J, Higginson IJ: Do specialist palliative care teams improve outcomes for cancer patients? *Palliat Med* 1998; 12:317-332.
4. Pritchard RS, Fisher ES, Teno JM, Sharp JM, Reding DJ, Kraus WA, Wennberg JE, Lynn J: Influence of patient preferences and local health system characteristics on the place of death. *J Am Geriatr Soc* 1998;46: 1242-1250.
5. Coombs RH, May DS, Small GW: *Inside Doctoring: Stages and Outcomes in the Professional Development of Physicians*. New York: Praeger Publishing, 1986.
6. Degner LF, Beaton JT: *Life-Death Decisions in Health Care*. Washington, D.C.: Hemisphere Publishing, 1987.
7. Trask AG, Faber DR: The intensive care unit—Who's in charge? *Arch Surg* 1990;125:1105-1108.
8. Belzberg H: The intensive care unit: Who's in charge? *Clin Neurosurg* 1989;35:63-67.
9. Manian FA: Whiter continuity of care? *N Engl J Med* 1999;340:1362-1363.
10. Higginson I, Priest P, McCarthy M: Are bereaved family members a valid proxy for a patient's assessment of dying? *Soc Sci Med* 1994;38:553-557.
11. Desbiens NA, Mueller-Rizner N: How well do surrogates assess the pain of seriously ill patients? *Crit Care Med* 2000;28:1347-1352.
12. Lobchuk MM, Kristjanson L, Degner L, Blood P, Sloan JA: Perceptions of symptom distress in lung cancer patients: I. Congruence between patients and family caregivers. *J Pain Symptom Manage* 1997;14:136-146.
13. Zuckerman C, Mackinnon A: *The challenges of caring for patients near the end of life: Findings from the Hospital Palliative Care Initiative*. New York: United Hospital Fund, 1998.
14. Linder Pelz S: Social psychological determinants of patient satisfaction: A test of five hypotheses. *Soc Sci Med* 1982;16:583-589.
15. Williams B, Coyle J, Healy D: The meaning of patient satisfaction: An explanation of high reported levels. *Soc Sci Med* 1998;47:1351-1359.
16. Hays RD, Shaul JA, Williams VSL, Lubalin JS, Harris-Kojetin LD, Sweeny SF, Clearly PD: Psychometric properties of the CAHPS™ 1.0 survey measures. *Med Care* 1999;37:MS22-MS31.
17. Davis K, Collins KS, Schoen C, Morris C: Choice Matters: Enrollees' views of their health plans. *Health Aff (Millwood)* 1995;14:99-112.

18. Gawande AA, Blendon RJ, Brodie M, Benson JM, Levit L, Hügick L: Does dissatisfaction with health plans stem from having no choices? *Health Aff (Millwood)* 1997;17:184-194.
19. Kahn KI, Pearson MI, Harrison ER, Desmond KA, Rogers WH, Rubenstein LV, Brook RH, Keeler EB: Health care for black and poor hospitalized Medicare patients. *JAMA* 1994;271:1169-1174.
20. Todd KH, Samaroo N, Hoffman JR: Ethnicity as a risk factor for inadequate emergency department analgesia. *JAMA* 1993;269:1537-1539.

Address reprint requests to:

*Joel Cantor, Sc.D.*

*Professor and Director*

*Rutgers Center for State Health Policy*

*317 George Street*

*Suite 400*

*New Brunswick, NJ 08901*

*E-mail: [jcantor@cshp.rutgers.edu](mailto:jcantor@cshp.rutgers.edu)*

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