Lack of Concordance between Physician and Patient: Reports on End-of-Life Care Discussions

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ABSTRACT

Objective: To study the effectiveness of patient physician communications regarding health care choices at the end of life. We studied communications occurring between physicians and their patients who had either terminal cancer or congestive heart failure, with less than 6 months to live.

Methods: This pilot study used in-person interviews with 22 physicians and 71 of their (matched) patients. Subjects provided paired responses to questions regarding their conversations related to end-of-life care, including resources, attitudes, and preferences. We calculated the concordance of patient and physician reports about these discussions. We examined the physicians' and the patients' agreement on the patient's diagnosis, and on whether a variety of care options were discussed. We then measured whether physicians' were aware of their patients' preferences for pain management and for place of death. Finally, we measured physicians' knowledge of whether religious/spiritual concerns or financial concerns had affected their patients' decisions regarding end-of-life care. Both bivariate and multivariate models were used.

Results: As a whole, the concordance scores were poor; however, concordance varied across domains of issues discussed. Patients with less education had significantly lower concordance scores.

Discussion: We have identified domains in which the physicians and patients may be least effective in discussing end-of-life care options. Findings may help in designing interventions to improve communication, especially for patients with less education.

INTRODUCTION

THE PURPOSE OF THIS PILOT STUDY was to evaluate the effectiveness of patient physician communications regarding health care choices at the end of life across a number of domains. Studies have consistently found that patients who talk about their preferences for end-of-life care with their physicians and family members feel less anxiety, feel more involved in their med-

ical decision-making, and perceive their physicians as having a better understanding of their needs (see Kass-Bartelmes et al.,¹ Ditto et al.,² and Smucker et al.³). However, the decision to use palliative care is often complex, and involves a high degree of discretion on the part of the physician, as noted by Lunney et al.,⁴ Feters et al.,⁵ and Christakis et al.⁶ Several research studies have indicated that often terminally ill patients are not participating fully in advance care planning,

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and they are receiving care that is inconsistent with their preferences.⁷ The SUPPORT Study is an especially good example of work that documents this problem in great detail by measuring patients' rates of failure to discuss sensitive issues at the end of life.⁸

In order to begin to understand patient physician communication regarding decision-making at the end of life, it is useful to put the subject into the larger context of how patients and their physicians interact when making a series of health care decisions. Because of the differences and incongruities between the physicians' and the patients' perspectives, the two parties may have different definitions of the patients' "need" for end-of-life care. In 1973 Donabedian⁹ proposed a framework for examining possible barriers for patients seeking health care. In this model Donabedian differentiates the client's perspective (client estimates of conditions and situations requiring care) from the professional perspective (professional estimates of conditions and situations requiring care). In this model the physician focuses on illness, including its manifestation, progression, and treatment. In contrast, the clients are typically less focused on a "scientific view" of their problems, and more concerned about the impact of care on their lives, including discomfort and pain. This model seems particularly useful when trying to understand problems in patient physician communication regarding end-of-life care decisions.

One result of these differences in perspective may be that those patients who have more education might be more willing and able to understand the physicians' scientific perspective, and therefore experience less difficulty communicating with their physicians about end of life care, compared to patients with little education. Van Ryn and Burke¹⁰ have suggested that certain patient characteristics, including greater level of education, should facilitate patient-physician communications regarding end-of-life care. However, it is an oversimplification to conclude that there is a straightforward relationship between higher patient education and more effective patient-physician communication regarding end-of-life care issues. In the SUPPORT study Hofmann and colleagues found that fewer than one fourth of those seriously ill patients studied had discussed cardiopulmonary resuscitation (CPR) with their physicians. Moreover, of those patients who had not discussed CPR preferences with their physicians, 58% were not interested in doing so.¹¹ (These investigators also found that race was an independent predictor of wanting to discuss preferences for CPR, but not doing so, with black patients more likely to be in this group.¹¹)

Communication problems can arise from either the patient, the physician, or both. For example, Coppola et al.¹² reported that physicians were only 65% accurate in predicting patient preferences, even after reviewing the patients' advance directives. The need to train residents and physicians in communication and relational skills is also emphasized in several studies by von Gunten and colleagues.^{13,14}

In addition to these findings in the SUPPORT study (mentioned above) regarding racial differences in communications about end of life care, there are other reasons to believe that race is an important factor when examining this type of communication. Patterns of end-of-life care are quite different for Caucasians and African Americans in the United States, with fewer African Americans using hospice care. In the year 2000 only 8% of hospice use nationally was for blacks while 84% was for whites, whereas the population of the United States in that year was approximately 12% black and approximately 77% white.¹⁵ Flory et al.¹⁶ noted that while in 1980 whites and African Americans died in the hospital in equal proportions, by 1998 African Americans died as hospital inpatients more often than whites.

Ashton and colleagues¹⁷ have been asking whether racial and ethnic disparities in the use of health services are due to bias, patient preferences, or poor communications. Mebane and colleagues¹⁸ have found that physician race is associated with differences in attitudes and preferences regarding end-of-life care. Furthermore, Cooper-Patrick and colleagues¹⁹ found that African American patients rate their visits with their physicians as less participatory than whites rate their own visits. They also found that patients seeing physicians of their own race rated their physicians' decision-making styles as more participatory.¹⁹ It must be noted, however, that it is unclear whether patients' ratings of the participatory nature of their communications with their physicians is the same as better communication regarding end of life issues, since the study by Cooper-Patrick et al.¹⁹ looked at younger patients (mean age, 41) in primary care practices. This is clearly not the same population that usually participates in discussions of end-of-life care issues.

Because of these earlier studies, we included race as a variable of interest in this study, both in terms of patients' race and physicians' race, and also in terms of whether race differed between the patients and their physicians.

A variety of other patient factors, including religious and spiritual issues, also can affect a terminal patient's preferences for end-of-life care, as noted by Hart et

al.²⁰ and Daaleman et al.²¹ Only a few research studies have been done in these areas, despite the recognition of the need to gain a better understanding of how these issues affect choices of end-of-life care.

The purpose of this study was to focus on patient–physician communications regarding health care choices at the end of life. Specifically, we studied communications occurring between physicians and their patients who were diagnosed with either terminal cancer or end-stage congestive heart failure (CHF). The following hypotheses were explored:

H1: Overall, patients' communications with their physicians regarding end-of-life care options will be poor. The effectiveness of communication will vary inversely with the sensitivity of different issues/clusters of issues related to end of life care. Communication regarding factual issues and services available in the community will be most effective, whereas physician knowledge regarding patient preferences for end-of-life care and the factors influencing these preferences will be very poor.

H2: Demographic factors (race of physician, gender of physician, age of physician, patient's education, patient's age, patient's gender, and race of patient,) will be related to the effectiveness of the communications between physicians and their patients. In particular, those patients who have a higher level of education will experience more effective communication regarding all end of life issues. [[[end extract]]]

Our study adds to the existing research in several ways:

1. There has been little use of matched physician–patient dyads when studying communication about end of life care. One of the few studies that did use matched respondents was done recently by Goldstein et al.,²² but that study focused more narrowly on communication regarding the patients' prognoses. Our focus was much broader, and included a range of domains relevant to end of life discussions. The matched approach that we used allowed us to examine the perceptions of both patients and their physicians regarding a broad range of communications about end-of-life care. This matched approach also allowed us to better explore which patient and physician characteristics were associated with more effective communication patterns in each of the domains discussed.
2. Very few studies have focused on identifying the various domains in which end-of-life communication is better and the domains in which such communication is poorer. It is important to differentiate the concordance levels across various domains of interest, so that we can tell which patient and physician factors are most important for which domains. A better understanding of differences across domains may help us to tailor physician training and other interventions in those areas where the physicians may be least comfortable in their discussions with their patients.

METHODS

Instrument and measures development

A literature review was conducted to identify content areas (domains) for development of instruments. Four end-of-life domains were selected for use in this analysis as important in defining concordant patient–physician communications at the end of life. These are: certainty of diagnosis; options for end-of-life care (hospice, nursing home, home care, etc.); physician's knowledge of some of the important factors that may have influenced the patient's decisions regarding end-of-life choices (religious/spiritual values, financial concerns); and physician's knowledge of the patient's preferences for pain management and for place of death. The specific subdomains are represented by the data collected specifically from the questions in the patient information card (PIC) and matching patient interview items, and are presented in Table 1. Instruments for structured interviews were drafted and pretested for both physicians and patients. The final instruments were a physician interview, a patient interview and a PIC. As Table 1 illustrates, the specific questions on each instrument were worded at a level appropriate for the respondent, while attempting to maintain face validity of the questions in each subdomain of interest.

Each participating physician was interviewed, and also was asked to complete a PIC for each of his or her patients who agreed to be interviewed. The physician interviews included both open-ended and multiple choice questions regarding the physician's training, experience with end-of-life issues, knowledge of local resources for end-of-life care, and physician perspectives about patient preferences for care at the end of life. Early in the instrument development process our investigators decided to streamline physician in-

TABLE 1. CONTENT DOMAINS FOR END-OF-LIFE DISCUSSIONS, BY PHYSICIAN AND PATIENT QUESTIONS

<i>End-of-life domain</i>	<i>Subdomain</i>	<i>Patient question</i>	<i>Physician's report on patient information card (PIC)</i>
1. Diagnosis	Primary condition	Could you describe what your doctor is treating you for?	Patient's diagnosis
2. Topics regarding the need for various types of services.	Possible need for hospice care	Has your doctor talked with you about hospice care?	Discussed hospice care with this patient?
	Possible need for referral to skilled nursing facilities	In particular, has your doctor talked with you about nursing home care?	Discussed nursing home care?
	Possible need for referral to religious/spiritual support services	Has your doctor asked if you would like a referral to spiritual support or pastoral care?	Discussed desire for spiritual support? (includes church groups, pastoral care).
	Possible need for referral to psychological/social support services	Has your doctor asked if you would like a referral to a social worker or psychologist?	Discussed social or psychological support services?
	Where to seek emergency care, if an emergency occurred	Have you discussed with your doctor who you would call in case of emergency?	Discussed who to call in case of an emergency?
	Advance directives	Have you talked with your doctor about advance directives?	Discussed advance directives with regard to DNR status, use of tube feeding, ventilator support and use of ICU?
3. Physician's knowledge of two factors that may have influenced patient's decisions on end of life care	Whether the patient's religious or spiritual concerns were affecting the patient's choices of care	Does your religion or spirituality influence your decisions about healthcare choices? Does your income level have an impact on your health care decisions?	Do you (MD) believe that this patient's religion or their spirituality affects this patient's health care decisions?
4. Physician's knowledge of patient's preferences for pain management and place of death	Whether the patient's financial circumstances were affecting the patient's choice of care	Have you had to make decisions about your health care which are not really your preferences, but choices that were necessary because you do not have enough money?	Do you (MD) believe that this patient's income level has an impact on his/her health care decisions?
	MD knows patient's preferences for pain management	If you were to become sicker, and experience severe pain, how would you prefer that your doctor treat your pain?	Do you (MD) know the patient's preferences for management of severe pain?
	MD knows patient's preferred place of death	Where would you prefer to spend the last several days of your life?	Do you (MD) know the patient's preferred place of death?

ICU, intensive care unit.

interviews to be no more than 30 minutes. The PIC, a physician-administered questionnaire, was designed to meet the physicians' time constraints while ensuring that key items from the patient interview were matched with physician responses. The PIC contained yes/no and multiple choice items about the end-of-life care discussions physicians had with each of the individual patients who were interviewed for the study. If the physician's nurse filled out this PIC, the physician was asked to verify the responses. Study coordinators worked closely with the physician offices to collect PIC cards in a timely fashion.

The final version of the patient interview form included open-ended and multiple choice questions regarding patient demographics, and preferences for advance care planning. There were also specific items addressing the discussions patients had with their physicians about various aspects of advance planning. Patients were also questioned about the way that spiritual and financial concerns affected their care decisions. The patient interviews were designed to be approximately 45 minutes in duration, unless the patient wanted to take more time to talk after the interview was completed.

Additional information about the data collection methods and other questions that were part of this study can be found in two other articles by the same research team (see Zapka et al.²³ and Carter et al.²⁴).

Recruitment

A list of 160 physicians practicing in South Carolina was obtained from the State Medical Board of Licensing. This included Caucasian and African American physicians specializing in internal medicine, family practice, oncology, and cardiology who were from the five geographic regions in South Carolina. Out of these physicians, 149 were reached by telephone, and were introduced to the study. Of these, 69 agreed to receive a packet describing the study. As a result of early withdrawal and/or passive refusal to schedule an interview, 40 physicians were interviewed. Of these, 22 were able to identify patients who met our criteria for inclusion. While we would have preferred to have a larger, systematically selected sample, we recognized that we would actually end up with a much smaller convenience sample, because it is very difficult to recruit physicians for this type of study. The small honorarium could not really reimburse these very busy physicians for their time. Therefore, we interviewed physicians who self-selected, perhaps because of some interest in the study itself. Furthermore, we cannot tell if the patients whom these physicians

designated as meeting the study criteria were "typical" of their patients. There is no means of ensuring that those who agreed to participate in the study are representative of all patients who are terminally ill with cancer or CHF, in terms of their relationships with their physicians.

In spite of the use of a convenience sample, it appears that the respondents were actually quite representative of the population of interest. We did capture a diverse population, in terms of physician gender, race, age, specialty type, and in terms of patients' gender, race, age, disease type (see Table 2, and also the discussion of the population in the Results section).

Physician's offices were contacted to confirm that he/she was a practicing physician. Once the physician's practice was confirmed, the physician was sent an introductory letter about the research project. One of the project investigators, a physician, contacted each potential physician participant 7 to 10 days later, and confirmed that the letter was received, explained nature of the research, explained the study recruitment process, answered questions, and sought the physician's willingness to participate. If the physician agreed, he/she was mailed a packet of information regarding the study procedures. The study coordinator also set a date and time for the physician interview. Physicians were asked to identify up to eight of his or her cancer or CHF patients who were expected to live less than 6 months. Eligible patients were stratified by condition, race, and gender. The physician then contacted the eligible patients, to ask their permission to be interviewed for the study. Physicians also were asked to complete the PICs for each of their patients at the time of the physician interview.

If a patient agreed to be interviewed, then his or her contact information was forwarded to the study coordinator. The study coordinator then contacted the patient to set up the interview, at the convenience of the patient. Patients received an honorarium of \$50. The research methods were approved by the Medical University of South Carolina's Institutional Review Board.

Data collection and management

Trained interviewers were matched by race to each of the interviewees (patient or physicians). Interviewers used the instruments to document physicians' and patients' responses to the questions in face to face interviews. The interviewers were also responsible for the collection of the PICs from the physicians' practices. Patients were interviewed in their homes, and physicians were interviewed and completed the PIC in their offices.

TABLE 2. PHYSICIAN AND PATIENT CHARACTERISTICS, AND RELATIONSHIPS OF THOSE CHARACTERISTICS TO THE OVERALL CONCORDANCE SCORES

Physician variable	n (%)	Mean concordance score ^a	Patient variable	n (%)	Mean concordance score ^a
Physician race			Patient race		
Caucasian	10 (45%)	0.55	Caucasian	30 (42%)	0.54
African American	12 (55%)	0.48	African American	41 (58%)	0.50
Physician gender			Patient gender		
Male	17 (77%)	0.51	Male	29 (41%)	0.52
Female	5 (23%)	0.54	Female	42 (59%)	0.51
Physician specialty			Patient Education		
Primary care	10 (45%)	0.48	< High school	26 (37%)	0.45
Oncology	8 (36%)	0.53	High school graduate	16 (23%)	0.56
Cardiology	4 (18%)	0.55	College+	25 (35%)	0.55
			Missing	4 (6%)	—
Physician's geographic area			Patient age		
Urban	15 (68%)	0.51	30–64	40 (56%)	0.51
Rural	7 (32%)	0.53	65+	31 (44%)	0.52
Physician's age (M = 47.6 years, SD = 8.1)			Patient diagnosis		
<50	13 (59%)	0.52	Cancer	41 (58%)	0.53
50+	9 (41%)	0.51	Heart failure	30 (42%)	0.50
Self-reported end-of-life training of physician			Number of years this patient has been Followed by this physician		
Yes	12 (55%)	0.51	<4	23 (32%)	0.50
No	8 (36%)	0.53	4+	24 (34%)	0.55
Missing	2 (9%)	—	Missing	24 (34%)	—

^aThe 11-item concordance score is reported for the $n = 71$ physician-patient dyads.

Each study measure was independently double-keyed as it was entered into the study database. To assess the precision of the data management process, a random sample of 20% of the forms was selected for verification to the database. If data inconsistencies were identified, a written clarification request was resolved by the study investigator. Once verification was complete, the database was locked and translated into SAS data files.

Analysis methods

The items in the patient interviews were matched with the physician responses on the PICs. We derived a summary concordance score for each patient physician dyad.

Concordance scores. Concordance scores quantified the match of patient-physician reported communications regarding health care preferences and choices and for end-of-life care. Of the four domains of communication queried during the interviews, the first two (communication regarding diagnosis, com-

munication regarding various care options) relied on direct matching of physician responses with the patient responses, i.e., if the patient-physician responses matched, the dyad was coded as concordant. Scores in the remaining two domains (physician's knowledge of the patient's stated preferences for place of death and for pain management; physician's knowledge of financial and religious/spiritual factors influencing patient choices) were derived differently, to reflect a more meaningful interpretation. In particular, a score of concordance was awarded if the physician correctly identified the patient's stated preferences regarding pain management and/or preferred place of death, and concordance scores were awarded if the physician could correctly identify the patient's stated responses on whether religious/spiritual considerations influenced patient choices, and on whether financial considerations influenced patient choices. Agreement had to be true agreement, insofar as answers of "don't know" or missing responses could not be counted as concordant.

Note that in this study we were measuring concordance or agreement on what was and was not dis-

cussed. This means that if both the physician and the patient agreed that no conversation had occurred regarding the items in domains one and two (diagnosis, various care options), then that would be counted as concordance for that dyad. However, this concordance does not mean that the topic was discussed. For example, patients and their physicians in 34 dyads (almost half) agreed that they did not discuss hospice care. These 34 dyads are, however, counted as concordant because both the patient and the physician agreed that the topic was not discussed. Note that we are not measuring the quality of end-of-life care, but instead the concordance of patients' and their physicians' reports of their communications.

For each of the 11 questions (subdomains) measured for each patient physician dyad, agreement yielded a score of 1, while a discordant observation yielded a score of 0. Thus, for each dyad, a summary (or total) concordance score could range from 0 (no domains concordant) to 11 (all 11 domains concordant). To measure each of domains on the same metric, concordance scores were standardized by dividing the sum of the questions in each domain by the number of questions in each of the domains. This procedure yielded a score ranging from 0 to 1.0. Coded in this manner, the concordance scores reflect the percentage of items for which the patient and physician were in concordance in their responses.

Analysis. The distribution of the total concordance scores was evaluated prior to the multivariate analysis. While the Kolmogorov-Smirnov test for normality indicated a potential lack of fit,²⁵ a review of the empirical histogram overlaid with a normal density plot and a regression-based residual analysis suggested the deviation in distribution was minor. Therefore, the overall analysis of the total concordance scores proceeded, using a multiple regression model-building approach.

Simple means of the 11-item concordance scores were calculated for each of the physician and patient characteristics shown in Table 2. These bivariate associations were evaluated individually as predictors, using a simple linear regression model. Those characteristics bivariately associated with the total score at the $\alpha = 0.25$ level of significance became candidate predictors for a multiple regression model. The identified pool of candidate predictors is presented in Table 3.

The final multivariate regression model was developed from the candidate predictors, using a backwards selection process. Both main effects as well as first order interaction terms were considered in the modeling process. A type III level of significance of 0.10 was

needed in order for a predictor variable to remain in the model. The regression analysis included an adjustment for correlation of patient responses nested within each set of physician responses.

The final model fit was evaluated through a comprehensive residual analysis. The estimated means are based on least-squares estimates. To estimate the marginal mean for "race," equal weights were assigned to each education level to control for the effect of education. Similarly, the education marginal means were estimated for a population consisting of an equal number of Caucasian and African American physicians. To adjust for the hierarchy of patients nested within physicians, SAS PROC MIXED was used to estimate the final multiple regression model. Statistical analyses were conducted using the SAS system version 9.1 (SAS Institute, Cary, NC).

RESULTS

Characteristics of the respondents

The characteristics for the 22 physicians and 71 patients whose data are included in this congruence analyses are reported in Table 2.

Physicians sampled had a mean age of 47 (standard deviation [SD] ± 8) years, with 19 (SD ± 8) years of experience. Fifty-five percent of the physicians reported having had formal training on end-of-life issue, including courses or training in pain and symptom management or palliative care. Physicians were reasonably well represented in terms of race, specialty, and geographic location.

The patients participating in the survey, although not a random sample, also were fairly representative of the population of interest in terms of race, gender, and education level. The patients had a mean age of 64 years (SD ± 5). Both diagnoses were well represented, 58% for cancer and 42% for CHD (see Table 2). Note that this study was limited to Caucasians and African Americans because there were too few physicians and patients of other ethnic groups in this population to do matching of physicians, patients, and interviewers. This, of course, may limit generalizability to other racial or ethnic groups.

Results of bivariate analyses: patient/physician factors independently related to the concordance scores

Information on the estimated mean overall concordance scores associated with each of the patient and physician characteristics can be found in Table 2.

TABLE 3. PHYSICIAN AND PATIENT CHARACTERISTICS ASSOCIATED WITH THE ELEVEN-ITEM CONCORDANCE SCORE, BY LEVEL OF PATIENT EDUCATION, FOR THOSE PATIENT AND PHYSICIAN CHARACTERISTICS WHICH MET THE CRITERION OF α 0.05 FOR INCLUSION IN THE MODEL

Variable	Multivariable analysis ^a						
	Bivariate analysis		Tukey-adjusted <i>p</i> values for post-hoc comparisons of level of patient education ^b				
	Type III <i>p</i> value	Estimated mean concordance score	Type III <i>p</i> value	Estimated mean concordance score	< High school	High school graduate	College+
Physician race	0.045		0.091				
Caucasian		0.55		0.55			
African American		0.48		0.49			
Patient race	0.178		NS				
Caucasian		0.54					
African American		0.50					
Education	0.018		0.0496				
<High school		0.45		0.47	—	0.049	0.234
High school grad		0.56		0.57	—	—	0.701
College +		0.55		0.53	—	—	—
Does Race Match?	0.209		NS				
Y Black MD and PT		0.48					
Y White MD and PT		0.55					
N White MD/Black PT		0.48					
N Black MD/Black PT		0.55					

^aMultivariate analysis adjusted for correlation of patient responses nested within physician. Estimated means are based on least-squares estimates. To estimate the marginal mean for race, a hypothetical population consisting of equal numbers of individuals with each education level was used. Similarly, the education marginal mean was estimated for a population of equal numbers of Caucasian and African American physicians.

^bThe Tukey-adjusted *p* values are used to test how the three levels of education differ with respect to mean levels of concordance. For example, a comparison of patients with less than a high school degree (LS mean = 0.47) versus those subjects with a high school degree (LS mean = 0.57) is statistically significant (*p* = 0.049).

Bold type indicates the factor is statistically significant at <0.05 .

Patient characteristics

Differences associated with patient age and gender were very small, and of no significance. There are, however, significantly higher average concordance scores for patients with a higher education in the bivariate analysis.

Physician characteristics

Among the physician characteristics, only very small and nonsignificant differences were associated with physician age, gender, urban/rural location, whether the physician reported having had formal end-of-life care training, or the length of time that the physician had followed each of these patients. Some small differences were found related to physician gender, with female physicians having somewhat higher overall concordance scores, but these differences were

not significant. There were also small differences associated with physician specialty, with the specialists having somewhat better concordance scores, on average, than the primary care physicians but these differences were not significant either.

Physician race did appear to be associated with differences in concordance scores in the bivariate analysis, with Caucasian physicians having somewhat higher concordance scores (0.48 for African American physicians, compared to 0.55 for Caucasian physicians (*p* = 0.045).

Differences in concordance scores across domains of issues discussed

In the bivariate analysis, the proportion of physician-patient dyads with concordant responses varied greatly across the domains of interest. Concordance

scores ranged from lows of 14% for the physician's knowledge of patients' stated preferences regarding pain management, and for physicians' knowledge of the patients' stated preferred place of death to highs of 92% agreement regarding the patient's diagnosis (Table 4).

Differences in concordance scores by matching of patient and physician race

We were interested in whether the concordance scores would differ when the race of the patient and the race of the physician were the same, compared to when the races were different. We found that using the approach described above, those African American patients with African American physicians had lower estimated mean concordance scores, compared to the other three groups, but these findings were not significant (see Table 3). Note, however, that this is a bi-

variate comparison, which does not control for level of patient education.

Results of using the multivariable model

In order to decide which variables to include in the multivariate models, we considered which of the characteristics studied in the bivariate analysis were statistically significant at the $\alpha = 0.25$ level of significance. The variables of physician race, patient race, patient education and the racial matching of the patient and physician met this criterion (Table 3).

In the multiple linear regression model, after adjustment for the clustering of patients within physician, the physician's race and patient's education level were the only independent variables that remained statistically significant in association with the 11-item congruence score.

TABLE 4. PATIENT AND PHYSICIAN CONCORDANCE IN EACH OF THE CONTENT DOMAINS

<i>Content domain</i>	<i>Subdomains</i>	<i>Mean concordance score within each domain/subdomain</i>
1. Knowledge of patient's primary condition (cancer, CHF)	Discussed primary condition	91.6
2. Discussion topics regarding the need for various types of services.	Discussed possible need for hospice care	69.0
	Discussed possible need for referral to skilled nursing facilities	74.9
	Discussed possible need for referral to religious/spiritual support services	70.4
	Discussed possible need for referral to psychological/social support services	60.6
	Discussed where to seek emergency care, if an emergency occurred	49.3
3. Physician's knowledge of factors that influence patient's decisions	Discussed advance directives	59.2
	Physician knows whether the patient's religious or spiritual concerns were affecting the patient's choices of care	29.6
4. Physician's knowledge of patient's preferences for pain management and place of death	Physician knows whether the patient's financial circumstances were affecting the patient's choices of care	35.2
	Physician knows patient's preferences for pain management	14.1
	Physician knows patient's preferences for place of death	14.1

CHF, congestive heart failure.

One possible reason for the bivariate finding reported above of lower congruence scores for African American patients with African American physicians might have been the nonrandom distribution of the education level of these patients.

When examining the interaction of the education of the patient and the race of the physician using a multivariate model, interesting results were found (Table 3). A post hoc comparison of mean scores indicated that those individuals with less than a high school education had lower concordance scores than those who completed high school ($p = 0.049$) (see Table 3). Given this finding, we analyzed the estimated mean concordance scores for patients with African American physicians. We found that the mean concordance score for these patients was 0.49 (standard error [SE] of 0.02); by comparison, the mean concordance score for patients who had Caucasian physicians was 0.55 (SE of 0.03). Thus, the relative differences in the level of concordance scores across physicians' races persists after adjustment for education; however, statistical significant is at the trend level ($p = 0.091$)

*Differences in concordance scores
within each of the four domains of interest,
by level of patient education*

In order to investigate the differences of the patient's education on concordance scores in more detail, we calculated the estimated mean concordance

scores within each of the four end-of-life domains, controlling for the patient's education level, as shown in Table 5. We found that the variations within one of these content domains were, indeed, associated with different patient education levels.

The concordance regarding the discussions of end of life services that are available, as measured by the concordance score of the six items comprising this domain, differed significantly by patient education level. A post hoc comparison of the three levels of patient education indicated that those patients with less than a high school education had less concordance with their physicians than those with a high school degree in this one domain. Note that the patient's education level was not significantly associated with the other domains, i.e., concordance related to knowledge of the patient's diagnosis, concordance regarding financial or religious/spiritual factors that influenced the patient's decisions regarding end-of-life choice, or concordance regarding the patient's preferences for place of death or pain management.

DISCUSSION

The overall finding is that there is a lack of effective concordance of patient physician communication regarding end-of-life discussions for patients who are terminally ill. There is also a lack of physician knowl-

TABLE 5. PERCENTAGE OF PHYSICIANS AND PATIENTS WHO WERE CONCORDANT
IN EACH END-OF-LIFE DOMAIN, BY LEVEL OF PATIENT EDUCATION

<i>End-of-life domain</i>	<i>< High school (n = 26)</i>		<i>High school (n = 16)</i>		<i>College + (n = 25)</i>		<i>p value^a</i>
	<i>Mean</i>	<i>SE</i>	<i>Mean</i>	<i>SE</i>	<i>Mean</i>	<i>SE</i>	
Diagnosis	0.84	0.06	0.88	0.07	1.00	0.06	0.128
Discussions of end of life services that are available	0.51	0.04	0.70	0.06	0.71	0.04	0.004
Physician's knowledge of factors that influence the patient's decisions regarding end-of-life choices (financial, religious/spiritual)	0.36	0.08	0.38	0.09	0.30	0.08	0.785
Physician's knowledge of the patient's preferences for pain management and place of death	0.20	0.05	0.16	0.06	0.08	0.05	0.218

^aPercentages were estimated separately for each end-of-life domain, using a mixed model that adjusted the standard errors for correlation of patients nested within physicians. Presented means are model-based (LS Means).

SE, standard error.

edge regarding patient preferences for pain control and for place of death, and the financial/religious factors that may influence these preferences. This observation of poor communication is consistent with hypothesis 1, and also with the studies cited in the literature review, especially the SUPPORT studies.¹¹ Note, however, that in this study we have confirmed results from the earlier studies by using a matched sample of patients and their physicians.

Most physician characteristics (gender, specialty, age, urban/rural location, the number of years that they had followed the patient, and whether the physician had end-of-life training), were not significantly associated with the overall (eleven item) concordance scores. This lack of findings may be due in part to a small sample size, and insufficient power to test these relationships. However, these findings need to be better understood, especially with regard to the lack of significance in predicting higher concordance scores for physicians who received training in end-of-life care.

The one physician factor that does appear to be somewhat associated with the concordance score is physician race, with the dyads having Caucasian physicians receiving the higher concordance scores; however the level of significance decreased to a trend once adjusted for patient education. The reasons for this finding are not understood.

Most of the patient characteristics (race, age, gender, diagnosis) were not associated with higher concordance scores. However, patient education is a significant factor: patients with less than a high school degree were less likely to have higher overall concordance scores. The discussions of end-of-life services that are available was where the strongest (statistically significant) differences across patient education levels were observed, with higher level of education positively associated with higher concordance scores.

A new finding of this study is that concordance varied according to the sensitivity of the subjects that are discussed (domains). This finding is consistent with our first Hypothesis, which stated that communication effectiveness would vary according to the content that was being discussed, with poorer communication in more sensitive areas of discussion, such as pain management and preferred place of death. We found that our concordance scores were much higher for those issues regarding the nature of the patient's illness, or regarding factual issues, i.e., what services are available in the community. However, for communication regarding the patients' preferences for end-of-life care and for pain management, and for communication regarding financial and religious/spiritual factors influ-

encing these preferences, the concordance scores were very low.

This lack of concordance in communication on the more sensitive issues regarding end-of-life decision-making would seem to be a serious problem for patients who are terminally ill. Because of poor communication regarding preferences for pain management and preferred place of death, it seems likely that many of those patients who would prefer (and could benefit from) highly skillful pain management at home are not likely to discuss such care with their physicians, and therefore it seems less likely that they will get the care that they might prefer if they were making informed decisions.

By identifying those domains where communication is the poorest, we can begin to gain an understanding of what training physicians need most, and support such training. Perhaps there is a need to evaluate whether the behavior/discussions encouraged by these training programs is well-focused on these areas. Better understanding is needed, to better tailor physician training in those domains where the physicians may be least comfortable in discussions with their patients.

Note, however, that there may be other reasons why physicians fail to communicate with patients about end of life care options. These additional reasons were discussed in the literature review, earlier in this article:

- The patient and/or the patient's physician may be in denial of the patient's approaching death, and may not want to discuss issues related to end-of-life care. Even though the physicians have identified the patients in our study as having less than 6 months to live, some of the physicians may not want to acknowledge this in their actual discussions with their patients. A physician may experience a sense of discomfort or failure when discussing approaching death with terminally ill patients and their families, and may therefore avoid discussions or handle them poorly. It is also clear from the SUPPORT studies that many seriously ill patients do not wish to discuss their preferences for end of life care.
- Some physicians may lack knowledge of the existence of end-of-life resources in the community, and therefore not bring up such options. As mentioned earlier, only a small proportion (42%) of the patients reported that their physicians discussed hospice care. Some physicians may be reluctant to discuss hospice options because of their limited understanding of the Medicare hospice benefits.
- Some physicians may believe that the available end-of-life care options will be unacceptable to some of

their patients, in terms of what they believe about these patients' perceptions and preferences. They may, therefore, decide not to discuss these care options.

- Physician may feel that they do not have time for these types of discussions.

If one (or more) of these problems occurs, then it is likely that effective communication regarding end-of-life care options will not take place between physicians and their patients. If high-quality end-of-life care is to be made available to all people who desire such care, then the lack of effective communication regarding end of life decision making needs to be addressed. Physicians must either receive some form of effective assistance to overcome their reluctance to discuss end of life choices with their terminally ill patients, or else they must be guided/encouraged to understand the need to refer these patients to appropriate skilled counselors (nurse, psychologist, pastor) for these important discussions regarding preferences for pain management, preferred place of death, and related issues. If the physicians refer their patients to discussions with other professionals, then it is important to coordinate care, so that the physicians receive some feedback regarding their patients' preferences and concerns.

Whoever is attempting to carry on these discussions (physician or a counselor) must understand that they have to take into account the patient's education level, in order for these discussions of end-of-life care options to be effective.

While these recommendations may sound simple, they certainly are not. The SUPPORT study confirmed that, "Enhancing opportunities for more patient-physician communication, although advocated as the major method for improving patient outcomes, may be inadequate to change established practices. To improve the experience of seriously ill and dying patients, greater individual and societal commitment and more proactive and forceful measures may be needed."¹¹

Strengths and limitations of this study

One of the strengths of this study is that it represents the first investigation of this issue in a southeast state with racial diversity of both patients and physicians. There is a good balance between races and diagnoses in respondents. These are important factors for a pilot study that explores an unexplored area. However, because the study used a convenience sample, representativeness cannot be assured, and generalizability may be limited.

The concordance score appears to be useful, and has good construct validity. It helps to differentiate the concordance levels across various domains of interest in end-of-life discussions, so that we can tell which patient and physician factors are most important for which domains.

Of course, there are also other limitations. We cannot confirm that either the physicians or the patients actually remembered their conversations accurately. While physicians were asked to confirm that the information on the PICs was correct, some time may have passed since their discussions, and their recall may have become less reliable. Also, because the sample size is fairly small we are limited in our ability to do multivariate analysis or to control for certain factors. Moreover, since there is nesting of patients within physicians, there is a potential for an increased rate of type I errors.

Areas needing further research

This study identified many areas that need further research. In particular, we want to understand what types of interventions will be most effective to facilitate or improve communication between physicians and their patients to improve comfort in end of life decision making. We have identified some aspects of the poor concordance regarding communications, such as which types of issues pose the largest problems in end-of-life discussions, and that patient education level has an effect on concordance scores. It is clear that more research is needed to determine how best to address these issues, so that more effective communications can take place between physicians and their patients regarding decisions about end-of-life care, especially when the patient has a low education level.

ACKNOWLEDGMENTS

We would like to acknowledge Walter Jones, Ph.D. and Mark Alexander, Ph.D., who were involved in the early stages of the project and the Department of Biostatistics, Bioinformatics and Epidemiology's Data Coordination Unit for data management assistance.

This research was supported by AHRQ-funded EXCEED 1P01HS10871

REFERENCES

1. Kass-Bartelmes BL, Hughes R: Advance care planning: preferences for care at the end of life. *J Pain Palliat Care Pharmacother* 2004;18:87-109.

2. Ditto PH, Danks JH, Smucker WD, Bookwala J, Coppola KM, Dresser R, Fagerlin A, Gready RM, Houts RM, Lockhart LK, Zyzanski S: Advance directives as acts of communication: A randomized controlled trial. *Arch Intern Med* 2001;161:421–430.
3. Smucker WD, Ditto PH, Moore KA, Druley JA, Danks JH, Townsend A: Elderly outpatients respond favorably to a physician-initiated advance directive discussion. *J Am Board Fam Pract* 1993;6:473–482.
4. Lunney JR, Foley KM, Smith TJ, Gelband H (eds): *Describing Death in America: What We Need to Know*. Washington, D.C: Institute of Medicine National Research Council of the National Academies, The National Academies Press, 2003.
5. Fetters MD, Churchill L, Danis M: Conflict resolution at the end of life. *Crit Care Med* 2001;29:921–925.
6. Christakis NA, Iwashyna TJ: Attitude and self-reported practice regarding prognostication in a national sample of internists. *Arch Intern Med* 1998;158:2389–2395.
7. Happ MB, Capezuti E, Strumpf NE, Wagner L, Cunningham S, Evans L, Maislin G: Advance care planning and end-of-life care for hospitalized nursing home residents. *J Am Geriatr Soc* 2002;50:829–835.
8. Haidet P, Hamel MB, Davis RB, Wenger N, Reding D, Kussin PS, Connors AF, Jr., Lynn J, Weeks JC, Phillips RS: Outcomes, preferences for resuscitation, and physician-patient communication among patients with metastatic colorectal cancer. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Am J Med* 1998;105:222–229.
9. Donabedian A: *Aspects of Medical Care Administration*. Cambridge, MA: Harvard University Press, 1973.
10. van Ryn M, Burke J: The effect of patient race and socioeconomic status on physicians' perceptions of patients. *Soc Sci Med* 2000;50:813–828.
11. Cole TB: Traffic safety experts prescribe treatment, sanctions to improve driving. *JAMA* 1995;274:1591–1598.
12. Coppola KM, Ditto PH, Danks JH, Smucker WD: Accuracy of primary care and hospital-based physicians' predictions of elderly outpatients' treatment preferences with and without advance directives. *Arch Intern Med* 2001;161:431–440.
13. von Gunten CF, Ferris FD, Emanuel LL: Ensuring competency in end-of-life care: Communication and relational skills. *JAMA* 2000;284:3051–3057.
14. von Gunten CF, Mullan PB, Harrity S, Diamant J, Heffernan E, Ikeda T, Roberts WL: Residents from five training programs report improvements in knowledge, attitudes and skills after a rotation with a hospice program. *J Cancer Educ* 2003;18:68–72.
15. U.S. Census website, CDC (National Hospice and Home-care Survey, Feb, 2004) Table 4.
16. Flory J, Xu-Young Y, Gurol I, Levinsky N, Ash A, Emanuel E: Place of death: U. S. trends since 1980. *Health Affairs* 2004;23:194–200.
17. Ashton CM, Haidet P, Paterniti DA, Collins TC, Gordon HS, O'Malley K, Petersen LA, Sharf BF, Suarez-Almazor ME, Wray NP, Street RL: Racial and ethnic disparities in the use of health services: Bias, preference, or poor communication? *J Gen Intern Med* 2003;18:146–152.
18. Mebane EW, Oman RF, Kroonen LT, Goldstein MK: The influence of physician race, age, and gender on physician attitudes toward advance care directives and preferences for end-of-life decision-making. *J Am Geriatr Soc* 1999;47:579–591.
19. Cooper-Patrick L, Gallo JJ, Gonzales JJ, Bu HT, Powe NR, Nelson C, Ford DE: Race, gender, and partnership in the patient-physician relationship. *JAMA* 1999;282:583–589.
20. Hart A, Kohlwees RJ, Deyo R, Rhodes LA, Bowen DJ: Hospice patients' attitudes regarding spiritual discussions with their doctors. *Am J Hosp Palliat Care* 2003;20:135–139.
21. Daaleman TP, VandeCreek L: Placing religion and spirituality in end-of-life care. *JAMA* 2000;284:2514–2517.
22. Goldstein NE, Concato J, Bradley DH, O'Leary JR, Fried T: Doctor-patient communication about prognosis: The influence of race and financial status. *J Palliat Med* 2005;8:998–1004.
23. Zapka J, Kurent JE, Hennessy W, DesHarnais S: Care at the end of life: Focus on communication and race. *J Aging Health* 2006;18:791–813.
24. Carter CL, Zapka JG, O'Neill S, DesHarnais SI, Hennessy W, Kurent J, Carter R: Physician perspectives on end-of-life care: Factors of race, specialty, and geography. *Palliat Support Care* 2006;4:257–271.
25. Hollander M, Wolfe DA: *Nonparametric Statistical Methods*. New York: Wiley-Interscience Publication, 1999.

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