



Published in final edited form as:

Patient Educ Couns. 2010 July ; 80(1): 3–9. doi:10.1016/j.pec.2009.10.018.

THE PHYSICIAN'S PROFESSIONAL ROLE IN END-OF-LIFE DECISION MAKING: VOICES OF RACIALLY AND ETHNICALLY DIVERSE PHYSICIANS

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Abstract

Objective—Previous studies have shown racial/ethnic differences in preferences for end-of-life (EOL) care. We aimed to describe values and beliefs guiding physicians' EOL decision-making and explore the relationship between physicians' race/ethnicity and their decision-making.

Methods—Seven focus groups (3 Caucasian, 2 African American, 2 Hispanic) with internists and subspecialists (n=26) were conducted. Investigators independently analyzed transcripts, assigned codes, compared findings, reconciled differences, and developed themes.

Results—Four themes appeared to transcend physicians' race/ethnicity: (1) strong support for the physician's role; (2) responding to “unreasonable” requests; (3) organizational factors; and (4) physician training and comfort with discussing EOL care. Five themes physicians seemed to manage differently based on race/ethnicity: (1) preventing and reducing the burden of surrogate decision-making; (2) responding to requests for “doing everything;” (3) influence of physician-patient racial/

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This manuscript has not been published or submitted for publication elsewhere. All co-authors listed have contributed sufficiently to the study to be included as authors. None of the authors has a potential conflict of interest regarding this paper.

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ethnic concordance/discordance; (4) cultural differences concerning truth-telling; and (5) spirituality and religious beliefs.

Conclusions—Physicians in our multi-racial/ethnic sample emphasized their commitment to their professional role in EOL decision-making. Implicitly invoking the professional virtue of self-effacement, they were able to identify racially/ethnically common and diverse ethical challenges of EOL decision-making.

Practice implications—Physicians should use professional virtues to tailor the EOL decision-making process in response to patients' race/ethnicity, based on patients' preferences.

Keywords

end-of-life decision making; physicians; race/ethnicity

INTRODUCTION

End-of-life (EOL) decision-making is an integral component of high quality health care. Physicians typically play an important role in the EOL decision-making process, specifically in decisions about initiating, withholding, or withdrawing life-sustaining treatments. EOL decision making is largely the province of older adults, a part of the U.S. population that is rapidly growing. By 2030, 20% of the U.S. population (71.5 million) will be over 65 years of age [1,2]. Ethnic minorities are the most rapidly growing segment of the U.S. elderly population [1,2]. Studying EOL decision-making for racial and ethnic minorities is becoming increasingly important, because health care providers serving these growing groups will need to provide culturally sensitive EOL care [3].

Research on the relationship between cultural, ethnic, or racial differences and decision-making for EOL care has mainly focused on patients [4–14] or surrogate decision-makers [13–23]. Physicians' involvement in how such decisions are made, in particular how race/ethnicity might be related to such decision-making, has largely been neglected, and only few studies have been conducted with physicians [14,24–28]. Additionally, most studies used quantitative surveys, which did not allow deeper insight into the decision-making process. We therefore conducted a qualitative study to explore how racially and ethnically diverse physicians perceive their role in the decision-making process about EOL care. The goal of this study was to explore qualitatively the values, concerns and beliefs that guide such physicians' EOL decision-making with and for their patients as well as the relationship between EOL decision making and physicians' race/ethnicity.

METHODS

Design and Subjects

With IRB approval from Baylor College of Medicine, we conducted focus group interviews with physicians between June and August 2004 as part of a larger study that included patients and surrogate decision makers [29]. Participants were recruited from a diverse sample of academic and private-practice physicians that included general internists and sub-specialists from member institutions of the Texas Medical Center. Physicians were staff, fellows (at least at the end of their first year of fellowship), or third-year residents nearing graduation). To ensure that all participants had sufficient clinical experience with EOL care, no physicians below postgraduate year 3 (PGYIII) level were recruited. Subspecialists were from the fields of gastroenterology, pulmonary/critical care, nephrology, oncology, and infectious diseases. Generalists included family practitioners and internists. Our goal was to include physicians who commonly treat patients in the end-stages of disease. Purposive sampling identified minority participants, while a convenience sample of Caucasian physician participants was

used. Physicians were contacted through e-mail and/or mail invitation, followed by a phone call.

Racial/ethnic homogeneity within groups was designed to facilitate ease of discussion among participants. Variation, e.g. in stage of training, experience, and subspecialty, allowed for a range of factors that might influence the decision-making process [30,31].

Procedures

The principal investigator (PI) and a research assistant reviewed consent forms with participants and answered questions regarding the study and/or participation in it. Participation was voluntary and consent could be withdrawn at any time. The PI left after consent information had been given. Focus groups with 3–5 participants were conducted separately for Caucasian, African American, and Hispanic physicians in a location convenient for participants. Belonging to a racial/ethnic group was determined by self-identification.

Each focus group lasted approximately 90–120 minutes, including time for the informed consent process. Group interviews were structured by a set of semi-structured guiding questions (see Table 1) to ensure elicitation of a variety of possible factors involved in the decision-making process. The guiding questions were developed by the research team (two geriatricians, an ethicist, and a social scientist) to focus on basic elements of EOL decision making and its relationship to race/ethnicity of physicians and patients. Moderators for the respective groups were race-concordant, female, and trained by a sociologist with extensive experience in moderating focus groups (MF). Participants also completed a brief questionnaire, which assessed demographics, training, and whether participants had an advance directive, living will, or power of attorney for themselves.

Analysis

Interviews were audiotaped and transcribed verbatim by a transcription service, with transcribers unaware of race or identity of participants. Investigators and the moderator of the respective group listened to the tapes and read the transcriptions simultaneously to check for accuracy of the transcriptions. Participants were assigned coded identifiers that were kept separately from the data, in a locked cabinet in the PI's office. During transcription, only participant codes were used to ensure confidentiality. If participants mentioned names of patients or physicians, transcriptionists deleted and transcribed them as e.g., “Mr. X” or “Dr. Y”.

All investigators reviewed the transcripts independently, identified passages disclosing values or concerns, and assigned codes indicating emergent categories. They then compared initial findings, identified and reconciled differences, and developed thematic elements that were placed into conceptually coherent categories of decision-making determinants, using an inductive grounded theory approach [32]. Findings were discussed with the other research team members who provided a critique, addressing clarity, consistency, and exhaustiveness. A reiterative process of rereading and recoding passages until final consensus was reached was used. In order to increase reliability and trustworthiness of the findings, all decisions were clearly documented during the analysis phase, so that the “decision trail” could be followed by others. Emblematic quotations illustrated the final categories and themes using ATLAS.ti 5.0.66 (Scientific Software Development GmbH, Berlin) to create a coded electronic data set and support all data management.

RESULTS

Twenty six physicians (11 Caucasians, 8 African Americans, 7 Hispanics) participated. Table 2 shows the demographic characteristics of focus group participants. Even though only few physicians had advanced planning documents for themselves (3 Caucasians and African Americans, 2 Hispanics), most physicians valued these documents and wanted their patients to have them.

Themes that Appear to Transcend Race and Ethnicity

Strong Support for the Physician's Professional Role—Physicians agreed on the importance of providing patients and families with evidence-based information regarding a disease's natural course and prognosis, in terms of both survival and anticipated functional outcome. They stated this information should be relayed jargon-free and tailored to the educational background of the patient or family. Physicians stated they felt that in their professional role they were similar to an “educator,” or “guidance counselor for health” who enables patients or families to make more informed decisions by addressing misconceptions that patients or families might have, after initially exploring what they already understood about the disease. Most physicians reported feeling it was helpful to focus on general values about EOL decision-making rather than getting into detailed discussions about procedures.

Responding to “Unreasonable” Requests—All physician groups reported using similar strategies in response to “unreasonable” requests, e.g., accepting CPR but not intubation. They said that faced with such a request they would again explain and clarify misconceptions: “Rectifying misconceptions is part of your job as educator: You can't pick and choose like it's a McDonald's where you can get the hamburger with or without the French fries, you know. Unrealistic requests need to be met with more education – and if they believe you, they will accept your explanations, and feel that you are part of the same team.” Some African American doctors said they felt it was occasionally appropriate to support such requests because it allowed the family a way out: they were not responsible for the patient's passing because they did not make the decision to withhold CPR. All physicians agreed if they were asked to do something that made them truly uncomfortable, they would offer the family the option of transferring care or try to involve an ethics committee. African Americans were quite frank about how they would talk to families and try to get them to see the situation more realistically, e.g., by saying “God doesn't do miracles every day.” All physicians expressed the importance of giving patients and families time to discuss and decide.

Physician Training and Comfort with Discussing EOL Care—Many physicians, particularly Caucasians, said they felt uncomfortable with initiating EOL discussions but acknowledged that it was “part of their job” and “had to be done.” Physicians agreed such discussions should be conducted in the outpatient setting and as early as possible. At the same time they said it was difficult to approach the subject on the first encounter with a patient or family without having yet developed good rapport and established trust. One African American doctor stated: “I usually don't get people to sign documents, but I raise their consciousness so they can think about it somewhere down the line, I want to plant the seed. Patients react fine to such discussions, I think it improves the relationship, because then my doctor knows what I want, that means `we're a team'.”

Many physicians, especially older ones, commented on their lack of formal training in initiating discussions about EOL care with patients. However, some younger physicians felt that in the last few years training had improved greatly in residency programs and that EOL issues were now beginning to be integrated into the medical school curriculum. Increased education made them feel more comfortable with the topic. In addition, physicians reported feeling more

comfortable with EOL discussions with increasing length of clinical experience as they learned from practice. Some physicians reported lacking knowledge about the legal aspects or the paper work involved in advanced planning and relied on the help of social workers for completion of such documentation.

Organizational Factors—Some physicians remarked positively that the computerized patient record system in Veterans Affairs hospitals prompted them to initiate EOL discussions. (The VA has several electronic reminders that pop up in a patient's electronic chart, and advance directives are one of them). The physicians reported feeling that they might be more successful in completing advance care planning with their patients when a “process,” i.e. a protocol for it was in place, and social workers helped patients complete the correct paper work. One barrier for initiating and documenting EOL discussions was such lack of support for physicians practicing in a county hospital, and time constraints for the ones practicing in a private setting.

Themes that Appear to be Specific to Race and Ethnicity

Preventing and Reducing the Burden of Surrogate Decision-Making—Hispanic doctors emphasized that they felt it was their duty to point out to patients that by not making decisions in advance they placed a heavy burden on family members, and that patients had the power to relieve that burden by discussing their wishes with their families. Additionally, participants stated that they told patients they might be able to prevent future family conflict if they stated their treatment preferences in advance.

While Hispanic physicians reported concentrating on directly telling patients that they could relieve burden for family members, African American physicians reported concentrating on their duty as physicians to relieve the burden of family members by making the decisions easier for them. These physicians said they accomplished this by reminding surrogates that they were not truly making the decision but rather allowing what the patient would have wanted to happen. African American physicians stated that, once a family reached a decision, it was important for physicians to support it, acknowledge that this decision was the right thing to do, and make family members feel confident that they were doing the best thing possible. African American physicians stressed the importance of establishing a good, trusting relationship with the family, which would then allow them to become the family's “guidance counselor for health.” Some African Americans reported feeling sometimes not only as a “teacher,” but also like a “minister,” who needed to prepare the family for the patient's passing. Though Caucasian physicians did not discuss the burden on surrogates when patients' wishes were unclear, they frequently would make recommendations by offering what they would do if their own family member was in a similar situation, a strategy all physician groups used.

Responding to Requests for “Doing Everything”—All physicians reported interpreting requests to “do everything” as a “red flag”, a sign to more thoroughly explore what “everything” meant to the patient or family, a time-consuming but necessary strategy to prevent future conflict. Each group speculated about reasons for such requests. Caucasian physicians stated that families who asked them to do everything might be in denial and unrealistic about the patient's situation and physicians' abilities to cure. Other families might feel obliged by a sense of familial duty to ask for everything, or because of their own fear of death. Last, they reported feeling that such requests also stemmed from confusion about the possibilities of modern medicine, especially in cases where multiple specialists were involved who might focus only on one specific organ system and thus potentially create false hope for families.

Hispanic physicians reported feeling that requests for doing everything subtly implied that a family was wondering whether the physician or team truly “tried to do the best for the patient,” and stated that such families needed special reassurance that this was indeed the case. Hispanic

physicians also reported feeling that extra effort in explaining the limitations of treatment was necessary to make sure family members didn't feel "like they were killing Grandma." These physicians stated that they often started discussions with the family that "doing everything" might inflict additional pain and suffering on a patient who would die regardless of the requested "heroic" treatment. Like Caucasian physicians, they described vividly, with graphic examples, side effects and impact on quality of life of certain interventions which would lead most families to change their mind about doing "everything." If the family trusted the doctor and believed he or she was on their side, more education by the physician would eventually lead to "good" decisions by the family.

African American physicians reported feeling requests to "do everything" could have several explanations. These could be expressions of guilt on the part of family members, possibly emanating from a feeling that, if they had taken the patient to the doctor earlier, they might have prevented a bad outcome. Additionally, African American physicians felt that African American patients might be suspicious that Caucasian physicians might not do "everything", with this distrust stemming from unequal treatment and a history of discrimination in the past. These physicians felt the better the physician-patient relationship was, the less likely it would be a family felt this way.

Both Hispanics and African Americans expressed how inappropriate they felt the phrase "doing everything" was. Hispanics pointed out that, literally, the opposite of "doing everything" was "doing nothing." An African American physician stated that talking about doing "everything" "creates a false sense of our ability to restore their loved one to whatever sense of function they may envision". Both groups mentioned how important it was to make clear that a patient would not be abandoned, and that comfort care was still treatment. African Americans discussed the importance of being clear to families that "doing everything" often meant causing pain and suffering. They felt obliged to present every potential treatment option, even if not all of them were viable options, and that long explanations as to why certain interventions were not feasible might be required.

Influence of Physician -Patient Concordance /Discordance—Most physicians said they thought that patients' knowledge about the disease, its natural course and patients' values, spiritual beliefs, and faith had greater impact on discussing EOL care than a patient's race/ethnicity. In particular, most Caucasian physicians reported thinking that a patient's race/ethnicity had minimal influence on how they discussed EOL decision-making: "These issues are colorblind and apply to everyone regardless of race." Practicing in Houston, Texas, they felt they had broad exposure to a racially/ethnically diverse population, compared to physicians in some other parts of the country. However, most of them felt uncomfortable with translations, fearing loss or misinterpretation of important facts.

In contrast, African American physicians said they thought they approached EOL discussions with patients of their own race differently than with race-discordant patients, even though the content of the discussion would be the same. They reported feeling that some African American patients had deep mistrust of health care organizations because of past experiences. African American physicians said they thought that race-concordant patients trusted them more as they shared similar experiences, cultural background, and in particular had more familiarity with and understanding of their spiritual beliefs. "Blacks tend to be, uh, very religious individuals and so, if you're not a religious person yourself, if you really don't have that, the faith, and, really talk about God, - it's hard to get their trust,-that's why doctors who are not religious or don't show it may have it harder to gain black patients' trust." Another physician remarked: "Being black treating black patients gives you an advantage because I feel what they feel.. I know what they're going through. And not only that culturally we have very similar beliefs, we have similar backgrounds. Just that fact alone is going to make them more likely to trust

me than they would a Caucasian - patients can better identify with doctors of their own race and doctors can better understand what they are going through.” A few physicians in each group expressed that some patients had “higher expectations” for race-concordant physicians.

To Hispanic physicians a patient's race and ethnicity mattered mainly as a language issue. They felt that both they and their patients felt more comfortable with EOL discussions when they spoke their native language. They believed it helped them develop a deeper relationship with the patient or family and gave them more certainty that the patient truly understood them.

Cultural Differences Concerning Truth-Telling—Hispanic physicians remarked several times on a culturally-based difference in opinion about truth-telling, and stated that Hispanic families sometimes would not want to tell the patient about a terminal diagnosis in order to protect the patient from bad news. One Hispanic doctor remarked on his personal difficulties in becoming comfortable with the U.S. practice of informing patients fully about their disease. African Americans and Caucasians also commented on ethnic differences in truth-telling and felt that such differences mostly occurred with Hispanic, Asian, or Middle Eastern patients.

Faith, Spirituality and Religious Beliefs—Some physicians in both Caucasian and Hispanic groups did not think their own faith or religious beliefs had any influence on their decision-making process. Caucasian doctors expressed concern about projecting their own values and, therefore, emphasized the need to stay “indifferent;” they thought their own religious beliefs were only of help in discussing EOL care if they were similar to the patient's because it might be comforting to patients to know their physician shared their faith. This would not help them make better decisions but might strengthen the connection with the doctor and thus improve communication. Some Hispanic physicians said they always asked about patients' religious beliefs and tried to accommodate accordingly because they thought patients' religious beliefs were very important in EOL decision-making. The Hispanic physician groups had the most diverse responses to the question about religious beliefs, ranging from not mentioning faith or religion at all because it could be interpreted as „too intrusive' to asking everyone about religious beliefs because they had experienced patients who “stopped stressing out when you talk to them about God” and that it restored patients' hope.

All African American physicians agreed on the importance of spirituality, especially for their African American patients: they always talked about God and spirituality to race-concordant patients and families. They remarked on the difficulty African Americans might have with withdrawing life support or limiting treatments based on faith: “Black people, with them being religious people, the withdrawing of everything seems like suicide, and, it seems like you're actively killing someone, and then if you actively kill somebody you can't go to heaven and things like this, you know. This might damn me to hell...and they don't want that responsibility- so I need to better explain difference to them, need to explain that the patient's disease process is what's killing them, you are not doing it, okay. So they don't tackle all that extra guilt, that's a big obstacle to getting a lot of these things done.” African American physicians also agreed that their personal faith influenced discussions only insofar as to be honest with patients and show integrity, but said they respected beliefs of others even if they did not share them. They reported feeling a special rapport with their African American patients because they shared their patients' spirituality which created a bond between them and their patients: “I feel quite comfortable to talk about spirituality. I use spirituality a lot- most of my black patients are spiritual, we discuss limitations on what we can do, and that they keep in perspective what God sees as healing versus what he doesn't – that we can sometimes not do everything. It allows them to bring out their hopes, and I never try to squash anyone's hopes, but I do give them some reality and then say `Now it's up to God!'”

They said they felt their patients were “so thankful to have a doctor for mind, body, and soul.” They stated they would tell patients to “ask God what He wanted them to do and then to decide accordingly.”

DISCUSSION

The commitment of this racially/ethnically diverse group of physicians to their professional role appeared to ground and guide their approaches to EOL decision-making with their patients. In their professional role, they emphasized concerns that appear to transcend race/ethnicity and identified aspects of EOL decision-making nuanced by race/ethnicity. The ethical concept of medicine as a profession was introduced by two British physician-ethicists, John Gregory (1724–1773) and Thomas Percival (1740–1804), in part to help physicians bridge social and class differences in the newly created infirmaries for the working sick poor. Gregory and Percival understood that focusing on such differences, when they are clinically irrelevant, undermines the physician-patient relationship [33]. They therefore called for physicians not to be biased by clinically irrelevant psychosocial differences between themselves and their patients but to take account of such differences when they are clinically relevant. This is the professional virtue of self-effacement [34].

The statements made by the physicians in our sample demonstrate their understanding of this professional virtue for EOL decision-making. These physicians made the important point that there are aspects of EOL decision-making that are independent of a physician's or patient's race/ethnicity, such as responding to seemingly unreasonable requests for intervention. At the same time, these physicians reported being able to identify how race/ethnicity is clinically relevant to these themes and therefore should nuance the physician's management of these fundamental ethical challenges. These physicians also made the important point that there are aspects of EOL decision-making that are very much shaped by race/ethnicity, especially truthful communication and respect for the patient's spirituality and religious faith. This follows a similar pattern of patient preferences where African American patients preferred to talk about spirituality during the EOL discussions, as reported in some previous studies [15,35].

In contrast, Blackhall et al. also reported that Mexican-American patients were more likely to favor a family-centered model of medical decision-making rather than one that focused on patient autonomy favored by most African American and Caucasian subjects [4]. Other studies have shown similar findings [8,15]. These are clinically relevant considerations and should be identified and addressed by physicians in the EOL decision-making process.

Some African American and Hispanic physicians in our sample reported feeling that patients were more comfortable with and confident in race/ethnicity-concordant physicians when discussing EOL care, supporting previous reports of minority patients rating race-concordant physician visits as more satisfactory or participatory [36–39]. Ability to understand patients' culture and background, increased trust (for African American physicians and patients) and ability to speak same language (for Hispanic physicians and patients) could be some reasons for this, as indicated by the focus group participants and found in previous studies with patients [36–38]. Even though the Caucasian physicians were aware of the history of discrimination among African Americans in the U.S. health care system, it seemed that they did not feel that it affected how they addressed EOL decision making with patients. Their reluctance to discuss religious beliefs is noteworthy because they might miss a very important aspect of EOL care that patients would like to discuss.

The lack of an organized `process', e.g. the computerized prompting in the VA system to discuss advance directives, which has been shown to increase completion rates of advance directives [39], was noted in most other hospitals. Another major barrier was time constraint. Other factors

were feeling uncomfortable with and lack of formal training in discussing EOL decision-making. Other studies have confirmed such gaps in medical training [40–42]. Therefore, these findings underscore the importance of racial/ethnic diversity among physicians and the urgent need for improving curricula in medical schools, residency programs, and continued medical education for practicing physicians regarding discussing EOL care; to improve quality of medical care. Younger physicians appeared more comfortable with discussing EOL care with patients, which may be related to improved efforts recently by many medical schools to include palliative care in the curriculum.

There are reports of deficient communication between physicians and patients, especially between African American patients as shown in previous studies [37,43–45]. All physicians in this sample approached EOL discussions in similar manner, except African American physicians who thought they approached EOL discussions with race-concordant differently than with race-discordant patients, even though the content of the discussion would be same. Data suggest that the poor communications noted in other studies may be caused more by a lack of trust rather than failure of the physicians to clearly explain options. More studies need to be conducted to better understand this relationship.

One limitation of this study, pertaining to all qualitative focus group studies, is related to number, size, and composition of focus groups. Although conducted in a large academic medical center, physicians practicing in the community were included. All participating physicians practiced in Houston, a city with large numbers of minority groups and cultures. Most physicians reported extensive exposure to different racial/ethnic groups unlike physicians in other geographic regions. A strength of the study is that information was obtained directly from physicians involved with EOL decision-making and purposively included racial/ethnic minorities. Ours is the first study to explore how the decision-making process for EOL care might vary among physicians from three racial/ethnic groups.

The differences we describe between groups may have been due to differing characteristics among groups other than race/ethnicity, such as practice specialty (generalist vs. subspecialist) and level of training (attending/fellow/PGY III). An exploratory, qualitative study is designed to generate hypotheses and does not permit meaningful subgroup analysis, much less subgroup analysis meant to test hypotheses. Whether and how themes that transcend race and ethnicity and themes that appear to be specific to race and ethnicity might vary by specialty, level of training, and other demographic factors are important questions for future research.

We did not triangulate our findings or use key informants. However, investigators were racially diverse and from different disciplines (e.g., medicine, social sciences, ethics), and each individually read and coded transcripts before reaching consensus. Finally, this was a retrospective study, and participants may have sought to avoid cognitive dissonance in their recall of events, i.e. they may not have reported things that in retrospect perhaps made them uncomfortable.

Conclusion

This qualitative study suggests that distinguishing aspects of EOL decision making that appear to transcend race and ethnicity from those that are race- or ethnicity-specific is an essential component of culturally sensitive EOL decision making. Physicians in our multi-racial/ethnic sample emphasized their commitment to their professional role in EOL decision-making. Implicitly invoking the professional virtue of self-effacement, they were able to identify racially/ethnically common and diverse ethical challenges of EOL decision-making.

Practice Implications

Physicians should use professional virtues to tailor the EOL decision-making process in response to patients' race/ethnicity, based on patients' preferences. Efforts should also be made to improve relevant training and education about EOL discussions among physicians, to increase their cultural competence in such discussions.

Acknowledgments

Dr. Braun was supported by a VA research career development award, RCD 02029 and a NIA grant R03-AG022144-01. This work was also supported in part by the Houston VA HSR&D Center of Excellence (HFP90-020).

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Table 1

Guiding Questions

| Guiding Questions | Probes |
|---|---|
| <p>1. How do you help a patient or surrogate decide for or against certain medical treatments or procedures when a true cure is no longer possible?</p> | <p>What we want to know is:</p> <ul style="list-style-type: none"> • Do you discuss these procedures with patients or their family members? If so, how do you discuss these procedures? If not, what are your reasons for not discussing these procedures? • Do you give guidance to patients and their family members regarding the usefulness of these procedures? If so, how? • Do you ever recommend against these procedures? If so, how do you discourage the use of certain procedures? • Do you ever recommend these procedures? If so, how do you encourage the use of certain procedures? What factors make you feel sure/unsure that what you recommend for a patient is what the patient would want? |
| <p>2. If you know that your patient will face specific decisions in the near future about specific medical procedures like CPR, mechanical ventilation, or tube feeding, how important is it to you to find out about such detailed decisions in advance?</p> | <ul style="list-style-type: none"> • How do you find out what your patient wants (in terms of these procedures), or how do you help their family members come to a decision about these procedures? / [What steps do you take in determining the preferences of patients or their family members for certain procedures? • How comfortable are you in determining these preferences? What things matter most to you when you help patients or family members make medical decisions for a seriously ill patient? What are your goals for the care of someone who may be at the end-of-life? • How do you describe the chances of getting well, given the use of certain procedures, to seriously ill patients and/or their family members? |
| <p>3. We don't know very much about what physicians believe is important for patients or family members to know about making decisions at the end of life.</p> | <ul style="list-style-type: none"> • What things (Values?) seem to matter most to patients and family members when you help them make such treatment decisions for a seriously ill patient? How important do you think it is to patients or family members to make such detailed decisions in advance? |
| <p>4. Some people want "everything" done and get a lot more tests and procedures than others. Do you explore what patients or their family members mean by "everything"? If so, how? If not, what keeps you from doing so?</p> | <ul style="list-style-type: none"> • Do you point out to families that "everything" may lead to pain and suffering for the patient? • Sometimes patients or their family members make unrealistic requests regarding end-of-life treatment (such as wanting CPR but no intubation or vice versa). Do you discuss the unrealistic nature of these requests with patients or their family members? If so, what words do you use? If not, what keeps you from doing so? |
| <p>5. Do you think that you explain end-of-life treatments differently to patients of your own race/ethnicity than to patients or family members of a different race/ethnicity than yours? Does race/ethnicity of the patient influence your style of discussion? If so, how?</p> | <ul style="list-style-type: none"> • If yes, how is it different? If no, in what ways do you think it's not different? • Do you feel more comfortable explaining end-of-life treatments to patients of your own race/ethnicity than to patients or surrogates of a different race/ethnicity? • What do you do when you feel conflicted about the care for a patient that the family or patient requests but you feel is inappropriate for seriously ill patients? Could you describe some examples? Was the race/ethnicity of the patient different than yours? |
| <p>6. How important are your own religious beliefs or your faith to you when you help patients or their</p> | <ul style="list-style-type: none"> • What do you do when you feel conflicted about the care for a patient that the family or patient requests but you feel is inappropriate for seriously ill patients? Could you describe some examples? Was the race/ethnicity of the patient different than yours? |

Guiding Questions

family members
make decisions about
end-of-life care?

Probes

- Do you think that your own religious beliefs or faith influence your discussion with patients or their family members about end-of-life care? If so, in what ways?
-

Table 2

Characteristics of Physician Focus Groups Participants

| | Caucasian | African American | Hispanic | Total |
|--------------------------------|---------------|------------------|---------------|---------------|
| Number of participants: | 11 (42.3%) | 8 (30.8%) | 7 (26.9%) | 26 (100%) |
| Focus Group 1 | 3 | 0 | 0 | 3 |
| Focus Group 2 | 0 | 3 | 0 | 3 |
| Focus Group 3: | 0 | 0 | 3 | 3 |
| Focus Group 4: | 3 | 0 | 0 | 3 |
| Focus Group 5: | 0 | 5 | 0 | 5 |
| Focus Group 6: | 0 | 0 | 4 | 4 |
| Focus group 7: | 5 | 0 | 0 | 5 |
| Gender: | | | | |
| Male | 8 | 4 | 5 | 17 (65.4%) |
| Female | 3 | 4 | 2 | 9 (34.6%) |
| Mean age (range): | 37.6 (28, 56) | 36.3 (28, 45) | 35.6 (30, 43) | 36.3 (28, 56) |
| SD: | 8.8 | 5.3 | 4.1 | 6.6 |
| Practice: | | | | |
| Generalists | 7 (26.9%) | 8 (30.8%) | 3(11.5%) | 18 (69.2%) |
| Subspecialists | 4 (15.4%) | 0 | 4 (15.4%) | 8 (30.8%) |
| Level of training: | | | | |
| Attending | 8 (30.8%) | 6 (23%) | 4 (15.4%) | 18 (69.2%) |
| Fellow | 1 (3.8%) | 0 | 3(11.5%) | 4 (15.4%) |
| PGY III | 2 (7.7%) | 2 (7.7%) | 0 | 4 (15.4%) |
| EOL Self-planning: | | | | |
| Living will | 2 | 1 | 1 | 4 (15.4%) |
| Advance directive | 3 | 2 | 1 | 6 (23.1%) |
| Power of attorney | 2 | 2 | 0 | 4 (15.4%) |

All percentages were calculated with the denominator set as n=26.