Communication and Decision Making About Life-Sustaining Treatment: Examining the Experiences of Resident Physicians and Seriously-Ill Hospitalized Patients

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BACKGROUND: Despite evidence-based recommendations for communication and decision making about life-sustaining treatment, resident physicians' actual practice may vary. Few prior studies have examined these conversations qualitatively to uncover why ineffective communication styles may persist.

OBJECTIVE: To explore how discussions about life-sustaining treatment occur and examine the factors that influence physicians' communicative practices in hopes of providing novel insight into how these processes can be improved.

PARTICIPANTS AND APPROACH: We conducted and recorded 56 qualitative semi-structured interviews with participants from 28 matched dyads of a resident physician and a hospitalized patient or their surrogate decision maker with whom cardiopulmonary resuscitation was discussed. Transcripts were analyzed and coded using the constant comparative method to develop themes.

MAIN RESULTS: Resident physicians introduced decisions about resuscitation in a scripted, depersonalized and procedure-focused manner. Decision makers exhibited a poor understanding of the decision they were being asked to make and resident physicians often disagreed with the decision. Residents did not advocate for a particular course of action; however, the discussions of resuscitation were framed in ways that may have implicitly influenced decision making.

CONCLUSIONS: Residents' communication practices may stem from their attempt to balance an informed choice model of decision making with their interest in providing appropriate care for the patient. Physicians' beliefs about mandatory autonomy may be an impediment to improving communication about patients' choices for life-sustaining treatment. Redefining the role of the physician will be necessary if a shared decision making model is to be adopted.

KEY WORDS: communication; decision making; end-of-life care; medical education; ethics.

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In academic medical centers resident physicians routinely inquire about a patient's preference for life-sustaining treatment in a manner far different from those proposed in the literature.^{1,2} Even after discussing options for life-sustaining treatment, patients exhibit a poor understanding of resuscitation and their wishes are poorly understood by physicians leading to confusion about the future plan of care.^{3,4} There is clearly room for improvement in this domain and numerous authorities in the field have provided evidence-based recommendations to improve clinical practice.^{5–7} However, changing physicians' communication style has proven challenging.

The communicative practices of physicians can be linked to various models of decision making. The three models most widely discussed in the treatment decision making literature—paternalistic, shared and informed choice—lie along a continuum and can be differentiated according to the information exchanged and the locus of deliberation and decision making.⁸ Paternalistic decision making features a beneficent physician making medical decisions without eliciting patient preferences and sharing only the minimum information necessary to obtain consent.⁹ At the midpoint of the continuum is the shared decision making model which has received the majority of recent attention in the medical education, end-of-life and decision making literature.^{11–13} Here, the information flow is bi-directional with the physician providing medical information and the patient contributing their values and treatment preferences. Both patient and physician are assumed to *have* a preferred treatment option and *share* their preference with one another. In practice this has been difficult to implement.^{14,15}

At the other end of the spectrum lies the informed choice model in which the physician merely provides the relevant information and executes the patient's decision. Deliberation and decision making are carried out by the patient alone.⁹ This "mandatory autonomy" model espoused by some ethicists is not without its problems as patients are required to make complex decisions using information they may not understand.¹⁶ Likewise physicians experience moral distress when they are asked to provide care they believe not in the patient's best interest.¹⁷

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While descriptive, these models are “insufficiently explicit about the dilemmas of professional ethics” that arise within the doctor–patient decision making experience.¹⁸

In this paper we examine how resident physicians’ communication about life-sustaining treatment relates to their beliefs about their role in decision making. We explore how these practices affect patient care with the goal of providing novel insight into how these processes can be improved.

METHODS

Participants

Study participants represented two groups—resident physicians and the patient or surrogate decision makers with whom the residents had discussed resuscitation. We interviewed informants individually following their discussion of the patient’s preferences for life-sustaining treatment.

Residents rotating on inpatient internal medicine services during the six-month study period were eligible to participate (80/82 internal medicine residents). The program’s curriculum provided no specific training on communication about life-sustaining treatment. Resident participation was voluntary and confidential and all provided verbal informed consent. They were asked to identify a patient or surrogate decision maker with whom they had discussed resuscitation in the preceding 36 hours who was willing to be approached about the study.

Participants had to be greater than 18 years old and speak English. To ensure informed consent and the validity of patient responses, a 14 question screen of cognitive function (orientation and information subset of the Wechsler Memory Scale-revised)¹⁹ was administered to patients by the interviewer prior to obtaining consent. Patients with fewer than 11 correct responses were not eligible. If a family member participated in the discussion that individual was invited to participate in the

Table 1. Characteristics of Participants

Patients	n (%)
Age, mean (SD)	65.4 + 16.4
Male gender	15 (53.6)
Race/Ethnicity	
White	26 (92.8)
Black	2 (7.1)
Primary diagnosis, %	
Metastatic cancer	7 (25.0)
Congestive heart failure (EF<30%)	5 (17.9)
Cirrhosis	3 (10.7)
Pneumonia	3 (10.7)
Acute coronary syndrome/MI	2 (7.1)
Advanced dementia	2 (7.1)
Gastrointestinal hemorrhage	2 (7.1)
Other	4 (21.4)
Residents	
PGY year	
1	13 (46.4)
2	8 (28.6)
3–4	8 (25.0)
Male gender	17 (60.7)
Medical school	
US	24 (85.7)
International	4 (14.3)
Race/Ethnicity	
White	25 (89.3)
Asian	3 (10.7)

Table 2. Interview Topic Guide

Patient and surrogate interview	Physician interview
Preferences for life-sustaining treatment	Interpretation of the patient’s preferences
How their physician raised this topic	How and why the physician raised this topic
Understanding of resuscitation and mechanical ventilation	Impression of patient/surrogate understanding
Satisfaction with the discussion	Physician opinion of the decision
Whether the physician provided guidance or recommendations	Physician involvement in decision making

research interview along with the patient. When the discussion occurred solely with a surrogate decision maker that individual completed informed consent for participation. Surrogate decision makers were required to be greater than 18 years of age, speak English, and be a legally recognized surrogate.

We recruited 28 physician–decision maker dyads. One resident was interviewed about two patients. Sixteen interviews were with the patient alone, seven with the patient and a family member, and five with a surrogate decision maker alone. Characteristics of the physician and patient participants are shown in Table 1. In addition, family member participants included 10 women and 2 men and were most often the patient’s spouse. The study was approved by the institutional review board at both participating medical centers.

Interviews

Semi-structured interviews were completed with all participants by KD and a research assistant (a clinical psychologist trained in the interview technique). Interviews were conducted within 36 hours of the index discussion to maximize accurate recall of the event. A semi-structured interview schedule was designed to ensure continuity across interviews and was pre-tested for content and clarity using a panel of experts including physicians from internal medicine and palliative care. Table 2 contains the interview topic guide.

Analysis

All interviews were audiotaped and transcribed. ATLAS.ti qualitative data management software (version 5.2, Berlin) was used to facilitate data organization and coding. The unit of analysis was each physician, patient or surrogate pair. Analysis included multiple close readings using the constant comparative method.²⁰ KD initially read all transcripts and developed a code list through an inductive and iterative process allowing emerging data to inform future interviews. As the code list expanded with successive interviews, early transcripts were re-coded to ensure completeness and resonance with developing themes. All authors independently analyzed eight transcripts; consensus was reached through discussion. The coding scheme was applied by KD to the remainder of the transcripts. The illustrative quotations assigned to each code were then grouped and examined by all authors to ensure consistency in code usage. Coding categories were grouped to generate themes relevant to the research question.

We attempted to ensure the trustworthiness of the data in three ways: (1) member checking with the physician participants, (2) assessment of interview transcripts for consistency

Table 3. Themes and Subthemes Pertaining to Communication and Decision Making About Life-Sustaining Treatment

Themes	Subthemes
Physician approach to the discussion	Depersonalized disclaimers Use of scripts
Patients and families lack adequate understanding	Misconception of resuscitation Distinction between CPR, life support and vegetative state
Physicians question the decision	Unreasonable expectations Preferences appear inconsistent
Physicians withhold guidance	Not physicians' responsibility Respect agency and autonomy Neutralize input from family members
Physicians implicitly influence decision making	Normative framing "Shock" talk
Balancing roles and responsibilities	Internal conflict about roles and duties

in technique between the two interviewers, and (3) theme saturation, which involved recruiting new participants until no new themes were apparent. Verbatim quotes from the informants are included to further enhance credibility. Table 3 provides themes and subthemes pertaining to communication and decision making.

RESULTS

Approach to the Discussion

Resident physicians introduced decisions about resuscitation in a scripted, depersonalized and procedure-focused manner. These discussions were most often (75%) had on the day of admission, frequently as part of the initial history and physical exam. Twelve physicians (42%) reported using a "disclaimer" to normalize the need to discuss resuscitation:

"First I always use a disclaimer, 'I don't want to scare you with what I am about to talk with you about, but this is something that I talk with all of my patients about no matter what they are in the hospital for.'" (MD 1, PGY1 male)

In half of the interviews, residents described using a script to introduce the topic to the patient or family and referred to it as their "standard", "status quo", or "canned thing." For example:

"I always say that...I ask these questions about what they would want done if their heart stopped beating while they were in the hospital or if they stopped breathing. I would say 'Would you like us to do chest compressions—I always put my hands on their chest so they know what I mean—or would you want shocks to try to bring your heart back, or would you want a breathing tube inserted or hook you to a ventilator to help you breathe?'" (MD 20, PGY 3 female).

The focus in these discussions appeared to be on the actual processes of advanced cardiac life support with varying degrees of detail, including "medications that we can give to increase your heart rate, decrease your heart rate, or get it out of an irregular rhythm," "electrical paddles," and "pounding on their chest."

Inadequate Understanding

Following these discussions, several patients and family members exhibited a poor understanding of the decision they were asked to make; eight physicians (29%) shared this concern. One patient's wife stated her belief "that you give him mouth to mouth resuscitation, or the shock treatments." Another male patient shared his perception that "they just work with them, and they just try to get them breathing again and everything" and that the success rate was "maybe fifty-fifty." Throughout the patient and physician interviews, the distinctions between "CPR", "life support" and the potential of a vegetative state were blurred. Many patients expressed wishes similar to the following:

"(The doctor) was asking me if I would want to be resuscitated...at first I automatically just said yeah and then I got to thinking about it...if I am just going to be a vegetable, I wouldn't want to do that...do everything you can, but if I get to that point where there is just nothing, than just go on and let me go." (Patient 13, 35-year-old female)

One physician highlighted a pervasive misunderstanding held by both patients and physicians in many of the dyads:

"I think the thing patients have a very hard time distinguishing is ventilator versus resuscitation. Universally you will ask that question—do you want to be put on the breathing machine to try to bring you back... and they say 'Oh no,...I don't want to be a vegetable on the ventilator.' And I say 'No, no, no, they're two completely different questions. That's not what I'm asking.'" (MD 12, PGY3 female)

Questioning the Decision

Of the 28 dyads examined, six physicians (21%) stated that they were uncomfortable with the decision made by or for their patient—usually when the patient wanted resuscitation and the physician felt it was not in the patient's best interest. One physician cited several areas of concern regarding the decision of a 67-year-old man with multiple underlying medical problems:

"I think he is basically kind of just dangling on a very thin thread right now. I think his expectations are very unreasonable. And because of that, he struck me as the type of person that would not want anything to be done, and I don't think he would do well if we did something for him...I think it would be kind of more traumatic" (MD 8, PGY1 male)

Another illustrative case featured a patient who wanted "manual CPR" but would "definitely not" want to be intubated or on a ventilator. Her physician felt this was not a medically reasonable option because "if you are going to choose one, then

you need to choose the other because it is airway, breathing, circulation and I don't think patients understand that."

In some cases the physicians' disagreement with the decision was based on their failure to distinguish the patient's request to attempt resuscitation but not be ventilator-dependent. One patient's daughter reported:

"She wants all measures taken as possible, but if (she) has to stay alive on the machine, (she) don't want to live on the machine. But if she can go on the machine like a ventilator and then come back off, she's all for it." (Daughter of Patient 15, 81-year-old female)

The resident described this as unreasonable from a "medical standpoint" because he believed she would have a very low chance of recovery. He also perceived an inconsistency:

"They made it clear that (the patient's) mom had been on a breathing machine for a long period of time and that (the patient) didn't want to have that, but then she wanted everything done. So, it was...kind of contradictory." (MD 15, PGY4 male)

Withholding Guidance

Resident physicians did not advocate for a particular course of action to the patient or family member. Seven physicians (25%) explicitly disagreed with this practice saying that they "just told (the patient) both options" and do not provide their opinion—sometimes withholding it even when asked. Likewise, the majority of patients and families reported they did not receive any advice and said that the doctors "were just trying to explain to us...they said that it was up to us what to decide." Only one patient reported receiving an explicit recommendation from their physician about their plan of care. Physicians provided various explanations for this reluctance.

"It's not my job..." One physician felt the patient's decision was unreasonable and contradictory but accepted it without question:

"I never (provide a recommendation) and I say to all families it's not my job to recommend one way or the other. I just tell you what it is and it's a decision you make. I tell them if they have any questions, I would try to answer." (MD 15)

Another resident emphasized her interest in providing "objective" data for her patient, a 35-year-old woman with end-stage heart failure by stating that:

"I tried to avoid (providing guidance)...and be objective because I want the patient to make up her own mind and understand everything and not just have an opinion, and have objective facts so that she can have an objective decision about it." (MD 13, PGY2 female)

However, a moment later she shared her concern about the patient's poor understanding of her condition:

"She really doesn't understand what (her disease) means and her probably thinking CPR is something that would

save her, and in her case it probably would not. It would probably be more of a futile-type care." (MD 13)

Agency and autonomy. Speaking about a woman with metastatic lung cancer, one physician expressed his interest in the patient's ownership of the decision in this way:

"I think that's a personal decision. I feel like that is a decision she needs to make. I understand that patients who...have cancer their chances of surviving a code is less than 1%...and my goal would be for her to be aware of that. But...I want her to make her own decision and if she feels comfortable with that then I'm comfortable with that but I don't want to pressure her either way. I want the decision to solely be hers." (MD 22, PGY2 male)

Another physician shared a similar sentiment about a healthy 55-year-old man who was vocal about his decision to be DNR after his mother experienced a poor neurologic outcome following a cardiac arrest. The resident acknowledged feeling conflicted about the patient's decision but when asked if he tried to advise the patient differently replied:

"Not really because he seemed like he had thought about it a lot and was comfortable with his decision. Honestly, I feel like he should be full code because he is relatively young and relatively few medical problems, yet I can also understand where he is coming from." (MD 3, PGY2 male)

A neutralizing force. Three residents felt the input of a family member complicated the decision making process and inhibited them from sharing their medical recommendation for the patient. One described her experiences as follows:

"I felt (the patient's) daughter was taking an active part in the conversation, and she was encouraging her mother to say yes, is what I would say. So I felt like I almost had to be a mediator, you know, the neutral party because I'm sure if it were my mother I would probably want her to say yes too." (MD 7, PGY2 female)

The primary goal for these physicians appeared to be uncovering the patient's preferences for treatment revealing the high value placed on patient autonomy as one would expect in an informed choice model.

Framing

Although many physicians denied explicitly influencing individuals in these decisions, the manner in which they framed the discussion of resuscitation was not value-free or without bias. This influence manifested in two ways in these discussions.

"What we normally do..." and the alternative? Residents reported presenting resuscitation as the norm when they raised this topic with patients. As recounted by one resident:

"I said normally if your heart and lungs should stop, we would first put down a breathing tube down through

your mouth into your lungs and breathe for you. And then we would do chest compressions, start pounding on your chest. We would also use electricity and shock your heart and use medicines.” (MD 17, PGY1 male)

This physician was strongly opposed to performing CPR on this patient yet presented it as the normative option without specifying any alternatives.

“Shock” talk. Residents, and as a result patients and their families, all speak of “pounding” on the chest, putting “tubes down the throat”, “use electricity” to do “shock treatments” and “shooting the heart with medication.” When asked about resuscitation, one older patient shared his perception that “they always beat and bang on you and put things in you and all that to make you breathe...well they actually have went in and mashed their heart to get them started again.”

Another example was from a 57-year-old woman with metastatic lung cancer who was emotionally distraught at times as she described her experience:

“He was talking about a blood clot being in my lungs and he asked me if I was to go into respiratory failure and cardiac arrest would I want to be shocked and then he said something like he wouldn’t want to do it to me because it could be very painful and ...I might live like a vegetable... he said he’d have to go down my throat with a vent[ilator] down there to breathe for me and they would be poking and pounding on me and...I finally told him if this happened just don’t do it. I wasn’t in too good a frame of mind but I felt like that if I said anything other than ‘No, don’t do it’, he wouldn’t have discussed it with me.” (Patient 19, 57-year-old woman)

During the interview, the physician expressed his fear that her prognosis in the event of a cardiac arrest would be poor. He stated his goal was to share with her that resuscitation might induce harm.

Balancing Roles and Responsibilities

In one case, the resident’s description of his involvement in the decision making process revealed potential internal conflict about his appropriate role. He described his discussion with the wife of a 62-year-old man with metastatic lung cancer explaining to her that no curative options were available and “just temporizing measures” remained. At his suggestion, the family decided to pursue hospice. However when asked about his role in the decision making process he stated:

“Ah! I didn’t advise her. In fact, I even remember saying that the purpose of me speaking to her wasn’t to influence one way or the other, just kind of educate her. What I think is best...is they need to take what’s in their heart, take what they can from my clinical judgment and put those things together and make a decision.” (MD 14, PGY3 male)

He describes a shared decision making model yet seems hesitant to acknowledge that he actively participated in the family’s decision.

DISCUSSION

Our findings are among the first to provide a description of and rationale for the communicative practices of resident physicians as they discuss patients’ preferences for life-sustaining treatment. We further examine how these practices affect decision making for patients and surrogate decision makers. Residents’ approaches to advance care planning discussions may hinge on their beliefs about the roles patients and doctors should play in medical decision making.

The experiences of our participants indicate that residents primarily adopt a model of informed choice in their discussions about life-sustaining treatment; however, their communicative practices in these discussions, as perceived on both sides, are not inclusive enough to ensure autonomous informed decisions. The use of generic scripts and procedural descriptions without a discussion of risks, benefits, or outcomes may lead to what many patients and physicians acknowledge is misunderstanding. In employing this approach, what may actually be a value-laden medical decision is camouflaged as a depersonalized, hypothetical one—a common counterproductive behavior in communication about end-of-life care.²¹ Perhaps as a sign of their allegiance to this model and patient autonomy, the participants leave the decision to the patient in an incomplete model of “mis”informed choice. Meanwhile, the majority of patients may prefer a greater degree of physician involvement in end-of-life decision making²² in which case reliance on informed choice may be detrimental to acutely ill patients facing difficult decisions.²³

Several residents reported feeling distressed about the decision and such disagreements between providers, patients and families about life-sustaining treatment are well described.^{24–27} Yet even though many residents do not endorse advising their patients, their implicit communication practices may influence decision making in more subtle ways. Even minor differences in the ways options and outcomes are presented can impact the patient’s choice via framing effects²⁸ with older adults being particularly susceptible.²⁹

Why does this happen? Perhaps resident physicians are attempting to balance the role they believe they are supposed to play—one of mandatory autonomy and informed choice—with their responsibility for providing beneficent care to patients. As Quill and Brody¹⁰ argue, a “misunderstanding of the moral requirements of respecting patient autonomy” may entrench these physicians in a particular model of communication and decision making that impedes good practice. Perhaps they believe that to provide any guidance in end-of-life decision making lies too close to the paternalistic model no longer acceptable in the modern American healthcare climate. Our interviews contain little evidence of a shared decision making model that includes eliciting patient values or communicating preferences for treatment by residents. When viewed through this lens, one can see how as Heyland and colleagues²² state, “a persistent focus on patient autonomy, potentially prescribing roles for patients that they do not wish to play may be responsible for the persistent failure of the system to improve communication and decision making at the end-of-life.”

Prior studies have demonstrated that ethnic, cultural, and spiritual factors can all potentially influence the ways in which physicians and patients approach end-of-life decision making.^{30–31} This study included a small rather homogenous sample which precludes generalization. It does appear that

most residents regardless of ethnicity, gender, or PGY year, adopted a uniform method of addressing resuscitation decisions that were highly dependent on patient autonomy and informed choice.

The limitations of this study are important to note. We did not record the actual conversation between physician and the decision maker. As a result these self reported data are potentially open to recall bias. Nonetheless, in conducting the interviews within 36 hours, we believe we have reduced this bias as much as possible. Allowing participants to reflect on this discussion may have provided better insight into their practices. Patient recruitment was dependent on the resident physicians who chose to participate leading to self-selection bias. This was unavoidable given the need to protect patient privacy. Because our participants represent two medical centers served by one training program, the findings of this qualitative study with a small sample size may not be broadly generalizable but are worthy of future study.

We believe these findings are a step forward in understanding the difficulties involved in implementing a shared decision making model in advance care planning. Nevertheless, we recommend that residents be taught how to communicate about life-sustaining treatment and anticipate the challenges of using a shared model as others have delineated.^{13,14,32} One major challenge will include shifting the focus from depersonalized, procedural descriptions to conversations about acceptable health states.³³ This may mean a more inclusive curriculum that includes self-awareness of one's own implicit and explicit attitudes and values about physician involvement in decision making in end of life care.

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