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Responding to Families' Questions about the Meaning of Physical Movements in Critically Ill Patients

Ruth A. Engelberg, PhD, **Marjorie D. Wenrich, MPH**, and **J. Randall Curtis, MD, MPH**
Department of Medicine, School of Medicine, University of Washington, Seattle, WA, rengel@u.washington.edu, maxter@u.washington.edu, jrc@u.washington.edu

Abstract

Background—Families may have questions about the meaning of physical movement in critically ill patients for whom movements are likely involuntary. If unresolved, these questions may contribute to difficult communication around end-of-life care. This study used qualitative methods to describe physicians' responses to families' questions about the meaning of patients' movements in critically ill patients.

Methods—51 family conferences in which withdrawal of life support or discussion of bad news was addressed were audiotaped and analyzed with a limited application of grounded theory techniques. Patients were identified from intensive care units in four Seattle area hospitals. Two hundred twenty-seven family members and 36 physicians participated in the study.

Results—Family members' questions indicating lack of resolution about the meaning of patients' movements that were likely involuntary occurred in 6 of the 51 conferences (12%). Physicians used three approaches to respond to these questions: 1) providing clinical information; 2) acknowledging families' emotions; and 3) exploring the meaning of families' emotions. Physicians were most likely to provide clinical information in these situations and infrequently explored the meaning of families' emotions.

Conclusions—Physicians' responses to family questions indicating lack of resolution about the meaning of patients' movements that were likely involuntary can be categorized into three types. Physicians may be better able to respond to and resolve these questions by employing all three types of communication approaches. Future studies should determine if such responses can improve families' experiences and other outcomes.

INTRODUCTION

Disparate interpretations between physicians and family members of the meaning of movement by critically ill patients without decisional capacity may result in difficult decision-making about end-of-life care, legal and ethical disputes, resistance to organ donation, prolonged life support, or complicated bereavement.[1–8] The Terri Schiavo case is an example of the difficulties that may arise when family members assign meaning to apparently involuntary movements by patients who are in persistent vegetative states.[6, 9–11] Families may interpret

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Address correspondence and reprint requests to: Ruth A. Engelberg, PhD, Division of Pulmonary and Critical Care Medicine, Harborview Medical Center, Box 359762, 325 Ninth Avenue, Seattle, WA 98104-2499, Phone: (206) 731-3356, Fax: (206) 731-8584, Email: rengel@u.washington.edu.

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these patient movements as evidence of awareness [9, 10] and therefore may be reluctant to accept physicians' assertions that the patient no longer has meaningful cognitive activity. Despite these potential impacts on outcomes of care, we found no research examining how physicians approach and resolve families' questions about the meaning of patients' movements when physicians and families disagree about the meaning of these movements that physicians interpreted as likely involuntary. In this brief report, we describe physician-family interactions around the interpretation of patients' movements using audiotapes of family conferences in the intensive care unit. Our goal is to provide physicians and researchers with insight into potential types of physicians' responses to families' questions about the meaning of movement in critically ill patients who are without decisional capacity.

METHODS

We prospectively identified all ICU family conferences scheduled to occur between Monday and Friday where attending physicians anticipated discussions of withholding or withdrawing life-sustaining therapy or delivering bad news. Study procedures have been described previously and were approved by the University of Washington Human Subjects Review Committee.[12–14]

Of 111 eligible family conferences identified, 19 were excluded because a physician or nurse requested we not contact the family (two families were excluded for risk management reasons because of potential litigation and 17 were excluded because the physician or nurse believed the family was too distraught to participate). Twenty-four families refused to speak with study personnel. Of 68 families approached, 51 agreed to participate. The proportion of all eligible conferences identified that were recorded was 46% (51/111).

Family conferences were audiotaped, transcribed and then analyzed using a limited application of grounded theory techniques, including axial coding approaches in which higher level concepts or explanations are developed based on initial codes.[15] The unit of analysis was a speech turn or passage, beginning with one person's speech and ending when another person began speaking. Consecutive passages that pertained to a single topic or issue were analyzed as a group. One higher-level concept, "physicians' responses to families' concerns about patient movement," was based on passages in which families' questions about the meaning of patients' movements were a focus of the conference and represented understandings that diverged from those expressed by the clinicians. Three investigators developed a framework for categorizing physicians' responses to these passages that included the following three categories: 1) providing clinical information; 2) acknowledging families' emotions; and 3) exploring the meaning of families' emotions and concerns. To check the trustworthiness of assignment to these categories, a colleague not involved in framework development reviewed eight representative passages (8/43, 19%) and assigned them to one of the three categories; agreement with investigators was 100%.

Comparisons were performed between the characteristics of participants in conferences in which families' questions indicated lack of resolution about the meaning of patients' physical movements and conferences without such questions indicating lack of resolution. The chi square test for categorical variables and the t-test for continuous variables were used for these analyses; a p value of < 0.05 was chosen to indicate statistical significance.

RESULTS

Characteristics of the 51 conferences have been described.[13, 14] Questions indicating lack of resolution about the meaning of patients' movements [heretofore referred to as "unresolved questions"] occurred in six of the conferences (12%). These six conferences concerned 6 unique patients and were led by six different physicians. Table 1 summarizes the characteristics of patients, family members and physicians from the six conferences in which unresolved questions occurred and the 45 conferences in which such questions did not occur. Families in the six conferences with these unresolved questions were significantly more likely to be non-white than those in conferences without these differences ($p < 0.05$). Patients' diagnoses in these six conferences included intracranial hemorrhage, cardiac failure and respiratory failure. While diagnoses were not statistically significantly different for patients in the six conferences with unresolved questions, half of patients in these conferences had intracranial hemorrhages while only 13% of patients in the conferences without unresolved questions had intracranial hemorrhages.

In addition to the 6 family conferences with unresolved questions about the interpretation of patient movements, patients' movements were discussed in an additional 11 conferences for an additional 11 unique patients but there were no unresolved questions about patients' movements in these conferences. For example, in one of these conferences, both the family and physician agreed that the movements they saw were “reflexive” and “not a good sign”. These conferences did not contribute to an understanding of physicians' responses to such questions and therefore were not included.

In the six conferences containing unresolved questions, families asked about the meaning of a number of patient movements, including: whether the patient was listening and recognizing family members, opening or shutting eyes, breathing or trying to breathe, turning or moving head and limbs, and grimacing and feeling pain. Physicians' responses to these questions were contained in 43 grouped passages; these passages are the study's unit of analysis. Table 2 shows the number of passages and the type of responses for each passage in each of the six conferences. We provide examples of each category below.

1. Clinical information

The majority of physicians' responses fell into this category (25 of 43 grouped passages; 58%). Clinical information was primarily used to educate the family about the meaning of movements that were likely involuntary and often included an explanation of the physiology and implications of reflexive movements. In the following interchange, the physician confirmed the family's observation of variation in the patient's breathing patterns and explained the etiology and implications. The lengthy explanation provided a rationale for the movements about which the family had questions.

> FAMILY: What is it that allows him to know that there is a presence there, that there is someone there talking to him, which causes him to breathe faster or move his head or even open his eyes when we speak and not just [when we] do something to him. What reflex is it that causes his lungs to do that?
>
> PHYSICIAN: Sometimes reflexes actually make legs and arms move; those are reflexes of the whole spinal tract. And then what you're referring to is a really essentially responsive to signals; it's all kind of linked together. Basically, the brainstem is the deepest part of the brain, what controls his heart rate and his breathing. That part is not damaged. That's often the last stage that's working well, so that's why you're seeing him breathing on his own and his breathing pattern. In a lot of patients that have brain injury, either from a trauma, a hit to the head or, a stroke or something like this where you have not enough blood flow to the brain, you can see breathing patterns that vary quite a bit, and sometimes that's to external stimulus, sometimes it's just his brain regulating it, and sometimes his breathing will speed up and slow down or be very deep and expansive and then slow down. That's a natural part of that, but that's very different from the higher level things like the thinking processes, where

> he's recognizing what you're saying and trying to say something; all those processes, from everything we can tell, are not working. (Conference 2)

While some clinical information statements appeared to successfully clarify families' questions, other statements failed to resolve these questions as in the following example during which the family asked why the patient was able to move her legs if she was brain-dead.

> FAMILY: I know today that she moved her legs.
>
> PHYSICIAN: Yeah, those are reflexes generated from the spinal cord
>
> FAMILY: See, that's so confusing, for her to have that. (Conference 4)

Similarly, in the following example, the family member saw the patient blink her eyes and asked the clinician to explain what that might mean. In response, the clinician discussed how brain damage may be assessed but did not satisfactorily resolve the family's question about whether the patient's eye movements supported or undermined a diagnosis of severe brain damage.

> PHYSICIAN: Right now, the pressure is not a problem… but the bad thing about the brain is, once the brain is damaged, it doesn't regenerate, as opposed to other organs of the body, like the liver…. We can remove up to 90% of the liver and it will be fine but the brain, unfortunately, the brain, once the portion of the brain is damaged, it's very hard to recover.
>
> FAMILY: Okay, is there a way in the next couple of days to find out, and I may have missed this, but find out if there is brain damage?
>
> SUBJECT MD: Oh, actually we have this twice a day, we examine her twice a day, at least once in the morning and once in the evening, and, um, when the person is in the intubated, in the intubated condition, meaning that the tube is there, we give them some medicine to keep them sedated whether they are unconscious or not, because when you have a tube inside you, it's very uncomfortable for the patient, so we can make them really comfortable. And during that period, when you do the neurological exam, it's not reliable. So at least twice a day we take that medicine off and examine the patient, how she is doing. So this is how we test the brain function. (Conference 5)

2. Acknowledging families' emotions

While less frequent, physicians also responded to questions about patient movements by acknowledging the important role of the family and the difficult emotions felt by the family (17 of 43 passages; 40 %). For example, a clinician responded to a family's question about whether the patient could hear them by acknowledging the families' importance to the patient.

> "If anybody's voice [is going to get through to her], it's certainly going to be you guys." (Conference 1)

Another clinician acknowledged the family's confusion over the meaning of the patient's movements by using active listening:

> FAMILY: And it might sound silly, but I just, I just find the redness of her face and it looks almost like a slight feel of, not frustration, but it looks like there is some kind of response or…
>
> CLINICIAN: Like maybe she can hear you but not be able to respond.
>
> FAMILY: Right. (Conference 5)

Other acknowledgements of emotion were couched in the form of, “that’s a good question, but….” or “you may have seen that but we haven’t,” as in this example from the family of a man with traumatic brain injury who said that they were sure that the patient recognized their voices when they talked to him by breathing quickly or heavily with the “breath of excitement”:

> PHYSICIAN: And those are very personal feelings. It’s very hard… and I don’t deny that you’re feeling this, you know. At the same point….
>
> FAMILY: I really feel it.
>
> PHYSICIAN: Yeah, no, and I believe you. We’re trying to be just very objective. (Conference 2)

3. Exploring the emotional components of families’ questions

We found only one example where a physician responded to an unresolved question about a patient’s physical movements by both acknowledging the family’s emotions and giving the family “permission” to consider and explore these emotions. In this interchange in which the physician explained why it was unlikely that the patient could turn his head in response to the family’s conversation, the physician encouraged the family to take more time to discuss their questions before consider whether to withdraw life support.

> FAMILY: So where do we go from here?
>
> PHYSICIAN: What I think we need to do to a great extent is to all kind of end up on the same understanding and acceptance, and I say that in the broadest sense. Not meaning you’re not trying to accept it, it just means it takes time, to accept it in your heart and brain all at the same time -- what’s happened to him. Sometimes that takes some additional time… …I think it’s always, especially when there’s a lot of family and friends, it’s always often hard.
>
> FAMILY: I mean, the emotions are running so high now.
>
> PHYSICIAN: Right, exactly, nobody can really think and get it all together.
>
> FAMILY: I think my questions were, my inner thoughts were answered, the results of the test, I was afraid of that. (Conference 2)

It is also interesting to note that, although the family did not raise additional questions but rather suggested that they would like to meet again in a few days, the family decision-maker nonetheless indicated that her questions had been adequately answered. Conversely, we found examples when physicians missed opportunities to allow families to explore and express their emotions associated with unresolved questions about the meaning of the patient’s movements. In one example, the family asked what it meant when the patient grimaced in response to movement by the physical therapist. The physician responded that the grimace was reflexive and “not a particularly good sign, no, or [a] wonderful sign” (Conference 3). At this point, the physician changed the discussion by asking the family if there were other people who should be included in the next family conference; this might have been an opportunity to allow the family to further discuss their emotions about this distressing information.

DISCUSSION

The presence of reflexive movements by critically ill patients represents a potentially difficult situation for both families and clinicians because the clinical meaning of these movements may be misunderstood. The Terri Schiavo case was an extreme example of the problematic sequelae associated with conflict over the meaning of a patient’s physical movements.[9, 10] Experts call on clinicians to engage in mediation to achieve a family-centered resolution without involving the courts,[6, 9–11] but there is little research to guide clinicians on how to do this. Our report describes a method for categorizing physicians' responses to families' questions indicating lack of resolution about the meaning of patients' physical movements; it provides a structure for future studies of examine the family's experience with different types of responses from clinicians. In our study, unresolved questions about patients' physical movements occurred in only 12% of enrolled ICU family conferences concerning withdrawal of life support or delivery of bad news; however these unresolved questions may have importance for family members when they do occur.

In this study, physicians primarily responded to families' questions about the meaning of patients' physical movements by providing clinical information. Clinical information was, at times, appropriately responsive to families' questions. At other times, presentation of clinical information seemed an inadequate response and perhaps even evasive. There were a number of instances when clinicians provided long explanations of the patient's medical condition but did not directly answer the family's questions. Less frequently, physicians acknowledged the families' emotions or explored the meaning of these emotions. Even when physicians acknowledged families' emotions, they often qualified these acknowledgements with clinical information. Yet emotional acknowledgement and support are rated by families as important components of physician skills at end-of-life care[16, 17] and may improve families' experiences. In a qualitative study of families' willingness to forego life support, Swigart and colleagues mapped tasks that families accomplish as they reconcile themselves to their loved one's death. These include assimilating the loved one's death cognitively, emotionally, and morally, and involve a trusting relationship with the physician or clinician who guides care.[18] In our study, we were able to find only a single example of a clinician who supported the family's need to explore their emotions concerning patient movements in the difficult circumstances around withdrawing life support. In this example, the clinician suggested that the family might need more time to consider their feelings before making a decision. However, he did not directly elicit conversations about the family's emotions. We did, however, find instances when physicians could have asked further about families' feelings and emotions but did not do so; the absence of this communication approach highlighted its importance.

Overall, the physicians we observed were more likely to respond to families' questions about patients' physical movements with cognitive information without exploring or acknowledging the family member's affective perspectives that may predominate in such situations. Exploration of families' emotions with regard to this issue, although rarely seen in these conferences, may provide physicians with a better understanding of the true import of families' interpretations of patient movements and allow physicians to better address these questions.[19]

Studies show a high burden of anxiety, depression, and post-traumatic stress disorder among the families of critically ill patients; these symptoms increase among families of patients that died and also among family members who were involved in end-of-life medical decision-making.[20–22] These studies suggest that clinician skill at responding to family members' questions and concerns influence the development of such symptoms in family members. While this brief report can not provide specific directions to alleviate or prevent the development of these troubling family symptoms, our findings may provide some general suggestions for approaching these difficult situations. Future studies are needed to determine whether such exploration of families' emotions and interpretation of meaning will decrease family symptoms.

In our study, differing perceptions between families and clinicians about the meaning of patients' physical movements occurred more commonly during conferences with family members from racial and ethnic minorities. This finding must be interpreted with caution since our study was designed as a qualitative study and the sample was relatively small. Nonetheless, this finding is supported by a body of literature suggesting that mistrust toward and conflict with health care providers is more common among racial and ethnic minorities.[23]

This report has several limitations. First, we were able to enroll only 46% (51/111) of the eligible conferences. Physicians and family members aware of questions indicating lack of resolution over the interpretation of patients' movements prior to the conference may have been more likely to refuse participation. Therefore, our findings may under-represent the prevalence of these questions. However, since our goal was to understand physicians' responses rather than define prevalence, we believe this limitation doesn't negate our findings. Second, while diagnoses were not statistically significantly different between the patients who were included in these analyses and those who were not, half of the six patients had intracranial hemorrhages. This suggests that our observations may be more relevant and generalizable to those critically ill patients with brain injuries. Third, we describe three types of physicians' responses but, because of our small sample size and observational and qualitative design, we are not able to assess which responses lead to better quality conferences or higher family satisfaction. Further studies will be needed to assess the effect of such responses. Fourth, we audiotaped family conferences and reviewed the tapes and transcripts, but were not able to interview physicians. Interviews with physicians might have given us invaluable insights into their perspectives on the goals of their communication approaches as well as their evaluation of that communication. Therefore, our categorization is inherently limited by the data available to us. Nonetheless, this categorization provides direction for future research attempting to understand and improve family experiences.

This report describes three types of physicians' responses to families' questions indicating lack of resolution about the meaning of patients' physical movements that are likely involuntary. Although we are not able to directly relate these different types of responses to families' experiences, acknowledgement of families' emotions and an opportunity to explore the meaning of these emotions may allow physicians to more fully address and resolve families' questions before adverse outcomes occur for patients and families. Further studies are needed to identify whether such an approach would improve families' experiences, reduce symptoms of anxiety, depression, or post-traumatic stress disorder among family members, and resolve questions regarding the meaning of patient movements more quickly and, potentially, with less involvement of the courts.

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References

1. Breen CM, Abernethy AP, Abbott KH, Tulsky JA. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. Journal of General Internal Medicine 2001;16:283–289. [PubMed: 11359545]
2. Annas GJ. Culture of life" politics at the bedside--the case of Terri Schiavo. New England Journal of Medicine 2005;352:1710–5. [PubMed: 15784657]
3. Weijer C. A death in the family: reflections on the Terri Schiavo case. CMAJ 2005;172:1197–8. [PubMed: 15805148]
4. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsky JA. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. Critical Care Medicine 2001;29:197–201. [PubMed: 11176185]

5. Dosemeci L, Cengiz M, Yilmax M, Ramazanoglu A. Frequency of spinal reflex movements in brain-dead patients. Tanspl Proc 2004;36:17–19.
6. Bloche MG. Managing conflict at the end of life. New England Journal of Medicine 2005;352:2371–2373. [PubMed: 15944420]
7. Way J, Back AL, Curtis JR. Withdrawing life support and resolution of conflict with families. BMJ 2002;325:1342–5. [PubMed: 12468486]
8. Kollas CD, Boyer-Kollas B. Closing the Schiavo case: an analysis of legal reasoning. J Palliat Med 2006;9:1145–63. [PubMed: 17040153]
9. Gostin LO. Ethics, the constitution, and the dying process: the case of Theresa Marie Schiavo. JAMA 2005;293:2403–7. [PubMed: 15900011]
10. Quill TE. Terri Schiavo--a tragedy compounded. New England Journal of Medicine 2005;352:1630–3. [PubMed: 15784658]
11. Burt RA. Law's effect on the quality of end-of-life care: Lessons from the Schiavo case. Critical Care Medicine 2006;34:S348–54. [PubMed: 17057597]
12. Curtis JR, Engelberg RA, Wenrich MD, et al. Studying communication about end-of-life care during the ICU family conference: Development of a framework. Journal of Critical Care 2002;17:147–160. [PubMed: 12297990]
13. McDonagh JR, Elliott TB, Engelberg RA, et al. Family satisfaction with family conferences about end-of-life care in the ICU: Increased proportion of family speech is associated with increased satisfaction. Critical Care Medicine 2004;32:1484–1488. [PubMed: 15241092]
14. Curtis JR, Engelberg RA, Wenrich MD, Shannon SE, Treece PD, Rubenfeld GD. Missed Opportunities during Family Conferences about End-of-Life Care in the Intensive Care Unit. Am J Respir Crit Care Med 2005;171:844–9. [PubMed: 15640361]
15. Strauss, AL.; Corbin, J. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. Thousand Oaks: Sage Publications; 1998.
16. Curtis JR, Wenrich MD, Carline JD, Shannon SE, Ambrozy DM, Ramsey PG. Understanding physicians' skills at providing end-of-life care: Perspectives of patients, families, and health care workers. Journal of General Internal Medicine 2001;16:41–49. [PubMed: 11251749]
17. Wenrich MD, Curtis JR, Ambrozy DM, et al. Provision of emotional support and personalized care by physicians to patients nearing the end of life. Journal of Pain and Symptom Management 2003;25:236–246. [PubMed: 12614958]
18. Swigart V, Lidz C, Butterworth V, Arnold R. Letting go: Family willingness to forgo life support. Heart and Lung 1996;25:483–494. [PubMed: 8950128]
19. Back AL, Arnold RM. Dealing with conflict in caring for the seriously ill. JAMA 2005;293:1374–1381. [PubMed: 15769971]
20. Pochard F, Azoulay E, Chevret S, et al. Symptoms of anxiety and depression in family members of intensive care unit patients: Ethical hypothesis regarding decision-making capacity. Critical Care Medicine 2001;29:1893–1897. [PubMed: 11588447]
21. Azoulay E, Pochard F, Chevret S, et al. Family participation in care to the critically ill: opinions of families and staff. Intensive Care Medicine 2003;29:1498–504. [PubMed: 12856124]
22. Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. New England Journal of Medicine 2007;356:469–78. [PubMed: 17267907]
23. Smedley, BD.; Stith, AY.; Nelson, AR. Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. Washington, D.C: National Academies Press; 2003. Unequal treatment: confronting racial and ethnic disparities in health care.

Table 1

Demographic characteristics of the family conference participants

	Patients (n=51)		Family Members (n=169)[+]		Physicians Leading Conferences (n=35)[++]	
	Conferences without unresolved questions (n=45)	**Conferences with unresolved questions (n=6)**	**Conferences without unresolved questions (n=150)**	**Conferences with unresolved questions (n=19)**	**Conferences without unresolved questions (n=29)**	**Conferences with unresolved questions (n=6)**
# Female (%)	28 (51)	4 (67)	88 (59)	13 (68)	9 (31)	3 (50)
# Nonwhite (%)	8 (18)	3 (50)	22 (15)[*]	7 (37)[*]	4 (14)	1 (17)
Mean age (sd)	59.0 (20.5)	67.4 (19.3)	48.3 (15.8)	48.5 (15.9)	39.1 (10.1)	34.7 (4.6)
Mean years in practice (sd)	--	--	--	--	13.0 (10.9)	8.7 (5.3)
# Diagnoses (%)						
Intracranial hemorrhage	6 (13.3)	3 (50.0)				
Endstage liver disease or GI bleed	8 (17.8)	0				
Trauma	8 (17.8)	0				
Sepsis	7 (15.6)	0				
Respiratory failure	4 (8.9)	2 (33.3)				
Cardiac failure	4 (8.9)	1 (16.7)				
Other	8 (17.8)	0				

[+] 169/227 participating family members completed questionnaires on which these data are based

[++] 35/36 participating physicians completed questionnaires on which these data are based

[*] p <=0.05

Table 2

Types of physicians' responses in grouped passages to families' unresolved questions about the meaning of movement in critically ill patients

	Clinical Information: # Grouped Passages	**Emotional Acknowledgment: # Grouped Passages**	**Emotional Exploration: # Grouped Passages**	**Total: # Grouped Passages**
Conference 1	5	4	0	9
Conference 2	3	5	1	9
Conference 3	3	3	0	6
Conference 4	1	0	0	1
Conference 5	12	3	0	15
Conference 6	1	2	0	3
# Total Grouped Passages (%)	25 (58.1)	17 (39.5)	1 (2.3)	43