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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, J. Randall Curtis MD, MPH

Department of Medicine, School of Medicine, University of Washington, Seattle, WA 98104, USA

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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: Fifty-one 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 4 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 (12%) of the 51 conferences. Physicians used 3 approaches to respond to the following 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 3 types. Physicians may be better able to respond to and resolve these questions by using all 3 types of communication approaches. Future studies should determine if such responses can improve families' experiences and other outcomes.

1. 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

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* Corresponding author. Division of Pulmonary and Critical Care Medicine, Harborview Medical Center, Box 359762, Seattle, WA 98104-2499, USA. Tel.: +1 206 731 3356; fax: +1 206 731 8584.

E-mail addresses: rengel@u.washington.edu (R.A. Engelberg), maxter@u.washington.edu (M.D. Wenrich), jrc@u.washington.edu (J.R. Curtis).

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Table 1 Demographic characteristics of the family conference participants

	Patients (n = 51)		Family members (n = 169) [a]		Physicians leading conferences (n = 35) [b]	
	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 (n [%])	28 (51)	4 (67)	88 (59)	13 (68)	9 (31)	3 (50)
Nonwhite (n [%])	8 (18)	3 (50)	22 (15) *	7 (37) *	4 (14)	1 (17)
Age (mean [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)
Duration of practice (y), mean (SD)	-	-	-	-	13.0 (10.9)	8.7 (5.3)
Diagnoses (n [%])						
Intracranial hemorrhage	6 (13.3)	3 (50.0)				
End-stage liver disease or gastrointestinal bleeding	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				

* $P \leq .05$.

[a] Of 227, 169 participating family members completed questionnaires on which these data are based.

[b] Of 36, 35 participating physicians completed questionnaires on which these data are based.

involuntary movements by patients who are in persistent vegetative states [6,9-11]. Families may interpret 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 (ICU). 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.

2. 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 (Seattle, Wash) [12-14].

Of 111 eligible family conferences identified, 19 were excluded because a physician or nurse requested we not contact the family (2 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 3 categories: (1) providing clinical information, (2) acknowledging families' emotions, and (3) exploring the meaning of families' emotions and concerns. To check the trustworthiness of