



# Communication expectations of critically ill patients and their families

Jennifer N. Ervin

Division of Pulmonary and Critical Care Medicine, Department of Internal Medicine, University of Michigan, Ann Arbor, MI, USA

Correspondence to: Jennifer N. Ervin, PhD. University of Michigan, 2800 Plymouth Rd Building 14-130G, Ann Arbor, MI 48109, USA.

Email: jenervin@umich.edu.

**Abstract:** Little is known about specific expectations family members and other types of surrogates have regarding clinician interaction. The objective of this study is to describe communication expectations regarding clinician engagement when surrogates represent patients who are too critically ill to advocate on their own behalf. As part of a larger study, a panel of 44 former patients and surrogate decision makers of a 20-bed medical intensive care unit (ICU) housed within a large academic hospital in the Midwestern United States responded to an online survey. Findings suggest that participants held different expectations for different intensive care providers in that 98% expected to talk to an attending physician within 48 hours of their loved one being admitted to the ICU, while 88% expected to have spoken with a registered nurse, and 74% with a respiratory therapist. Only half expected to have talked with a resident or fellow, and a third to a social worker. Regarding communication frequency, 95% of participants expected to interact with the care team at least once a day, and 74% preferred for contact to be initiated by clinicians. Together this suggests that expectations for surrogate-clinician communication more closely aligned with current guidelines for family-centered care than they are with actual practice.

**Keywords:** Intensive care unit (ICU); caregiver; family; communication; expectations

Received: 31 July 2019; Accepted: 26 August 2019; Published: 20 September 2019.

doi: 10.21037/jecm.2019.09.02

View this article at: <http://dx.doi.org/10.21037/jecm.2019.09.02>

## Introduction

Family-centered care is defined as “an approach to health care that is respectful of and responsive to individual families’ needs and values” (1). In the intensive care unit (ICU), current guidelines recommend open or at least flexible visiting hours, and regular family meetings that are initiated within 24–48 hours (2). However, evaluations of actual practice indicate that these benchmarks are rarely met (3–6). Perhaps the most pressing question is not *how* clinicians can meet family members’ needs, but instead continuing to work toward identifying *what* behaviors constitute as family-centered care. For example, communication is cited by both surrogates and clinicians as families’ most important need, and yet, little is known about specific preferences and expectations for interacting with clinicians (1). Some basic questions remain that this study sought to answer—which clinicians do surrogates

expect to communicate with first, and how frequently do they expect to speak with them? Answering these questions have important implications for whether and to what extent clinicians’ behaviors and intentions align with surrogates’ needs and expectations.

## Methods

A panel of former patients and surrogate decision makers of a 20-bed medical ICU housed within a large academic hospital in the Midwest were recruited through a patient and family engagement program. A program administrator emailed a Qualtrics survey on behalf of the study team in order to protect program members’ identities, thus response rates are not known. All program members over the age of 18 were eligible to participate. Participation was voluntary and the study was deemed exempt by the institutional

review board.

As part of a larger study on surrogate-clinician communication, participants were asked to provide demographic information, and then were instructed to imagine that an adult family member or close friend has been admitted to the ICU and placed on mechanical ventilation due to fluid in their lungs; they (the participants) were to envision acting as their loved one's surrogate. Participants indicated which clinicians they expect to have talked to within 48 hours of their loved one being admitted to the ICU (the attending physician; registered nurse; respiratory therapist; resident or fellow; social worker), and how often they would like to interact with their loved one's care team (multiple times a day; daily; a few times a week; once a week; other). Participants also responded to the following statements: "I prefer to have the care team contact me, rather than having to contact them" and "I feel confident that I know how to reach my loved one's care team," both of which were measured on 5-point Likert-type scales anchored by 1 (*strongly disagree*), and 5 (*strongly agree*). These items were based on social network analysis concepts such as degree centrality and tie strength.

## Results

A panel of 44 participants completed the survey. A majority of participants were married white females in their mid-50's who had received some education (see *Table 1*). While relatively homogeneous, this sample corresponds with other samples of surrogates of critically ill adults (7). A single participant was omitted from the following analysis because they only filled out the first page of the survey (i.e., demographics).

When asked about their expectations for communicating with specific clinicians, 42 participants (98%) expected to talk to the attending physician within 48 hours of their loved one being admitted to the ICU. A total of 38 participants (88%) expected to have talked to a registered nurse, and 32 (74%) to a respiratory therapist. Only approximately half (23 participants) expected to have talked to a resident or fellow, and roughly a third (15 participants) expected to talk with a social worker (see *Figure 1*).

Participants expected frequent communication with their loved one's care team, with 44% expecting to be contacted multiple times a day, 51% expecting to be contacted daily, 2% expecting to be contacted a few times a week, and a single participant marked other, stating "more if health declines." Regarding their preference for communication to

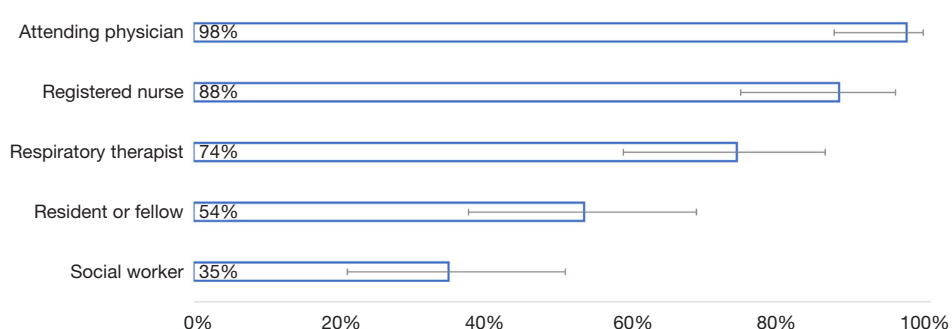
**Table 1** Participant demographics

Variable	Frequency (N=44) (%)
Age (mean, SD)	56.8 (12.8)
Female	36 (81.8)
White	43 (97.7)
Education	
Some college	26 (59.1)
Some graduate training	6 (13.6)
Employment	
Full time	14 (31.8)
Part time	4 (9.1)
Retired	19 (43.2)
Unemployed	5 (8.8)
Other	2 (4.5)
Married	30 (68.2)
Experience with mechanical ventilation	16 (36.4)

be initiated by the care team, 32 participants (74%) agreed or strongly agreed. Of those remaining, 6 participants (14%) were neutral, and 5 (11%) strongly disagreed. Lastly, regarding confidence in being able to reach their loved one's care team, 22 participants (51%) agreed or strongly agreed; 12 participants (28%) were neutral, and 9 (21%) disagreed or strongly disagreed.

## Discussion

This study suggests that surrogates have different expectations for engagement with different clinicians. For example, attending physicians were expected to reach out to family members within 48 hours, and to continue to initiate contact daily if not multiple times a day. General practice is discordant with these expectations. One study found that as few as 40% of patients and families had discussions with attending physicians about prognoses or end of life care across a 2-week ICU stay, in a sample where only 20% of patients were expected to survive the next 6 months (8). The expectations for frequent communication with registered nurses are slightly more realistic in that they (the nurses) are much more accessible to families and thus have been the target of several interventions seeking to improve family communication (9,10). More work is needed to understand the expectation of frequent communication with respiratory



**Figure 1** Participants' expectations for communication within 48 hours of a loved one being admitted to an intensive care unit by clinician type, with 95% confidence intervals.

therapists, especially considering that only approximately a third of participants had any prior experience with mechanical ventilation. Future studies might also explore underlying reasons why only half expected to interact with residents or fellows, whom often play central roles in care teams in academic hospitals.

Most participants preferred that the care team initiate contact. This could be related to the fact that only approximately half of the participants felt confident in knowing *how* to contact the care team. Interventions seeking to improve surrogate-clinician communication might consider targeting this knowledge gap.

This study is one of the first of its kind to describe specific expectations for clinician engagement. It is worth noting that these participants had recent experiences in the ICU; it is unclear whether families and surrogates with little to no prior experience in the ICU would hold similar expectations.

## Conclusions

Expectations for surrogate-clinician communication are closer in alignment with current guidelines for family-centered care than they are with actual practice. While efforts to improve family members' access to ICU providers should continue, it is important to consider the possible need to manage surrogates' expectations to help ensure that they are able to capitalize on opportunities to interact with members of the care team that they may not recognize as valuable sources of information.

## Acknowledgments

**Funding:** Dr. Ervin is receiving a grant from the National

Heart, Lung, and Blood Institute (K12HL138039).

## Footnote

**Conflicts of Interest:** The author has no conflicts of interest to declare.

**Ethical Statement:** Participation was voluntary and the study was deemed exempt by the institutional review board. The author is accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

**Disclaimer:** The study was conducted at the University of Michigan. However, the content is the responsibilities of the author alone and does not necessarily reflect the views or policies of the University of Michigan or at the National Heart, Lung, and Blood Institute.

## References

1. Davidson JE, Aslakson RA, Long AC, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Crit Care Med* 2017;45:103-28.
2. Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. *Crit Care Med* 2007;35:605-22.
3. Lilly CM, De Meo DL, Sonna LA, et al. An intensive communication intervention for the critically ill. *Am J Med* 2000;109:469-75.
4. Curtis JR, Engelberg RA, Wenrich MD, et al. 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.
5. Anderson WG, Cimino JW, Ernecoff NC, et al. A multicenter study of key stakeholders' perspectives on communicating with surrogates about prognosis in intensive care units. *Ann Am Thorac Soc* 2015;12:142-52.
  6. Liu V, Read JL, Scruth E, et al. Visitation policies and practices in US ICUs. *Crit Care* 2013;17:R71.
  7. Goldfarb MJ, Bibas L, Bartlett V, et al. Outcomes of patient- and family-centered care interventions in the ICU: A systematic review and meta-analysis. *Crit Care Med* 2017;45:1751-61.
  8. Teno JM, Fisher E, Hamel MB, et al. Decision-making and outcomes of prolonged ICU stays in seriously ill patients. *J Am Geriatr Soc* 2000;48:S70-4.
  9. Huffines M, Johnson KL, Smitz Naranjo LL, et al. Improving family satisfaction and participation in decision making in an intensive care unit. *Crit Care Nurse* 2013;33:56-69.
  10. White DB, Angus DC, Shields AM, et al. A randomized trial of family-support intervention in intensive care units. *N Engl J Med* 2018;378:2365-75.

doi: 10.21037/jeccm.2019.09.02

**Cite this article as:** Ervin JN. Communication expectations of critically ill patients and their families. *J Emerg Crit Care Med* 2019;3:48.