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*Brief Report*

# Strategies for Enhancing Family Participation in Research in the ICU: Findings From a Qualitative Study

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## *Abstract*

**Context.** Family members of critically ill patients who participate in research focused on palliative care issues have been found to be systematically different from those who do not. These differences threaten the validity of research and raise ethical questions about worsening disparities in care by failing to represent diverse perspectives.

**Objectives.** This study's aims were to explore: 1) barriers and facilitators influencing family members' decisions to participate in palliative care research; and 2) potential methods to enhance research participation.

**Methods.** Family members who were asked to participate in a randomized trial testing the efficacy of a facilitator to improve clinician-family communication in the intensive care unit (ICU). Family members who participated ($n = 17$) and those who declined participation ($n = 7$) in Family Communication Study were interviewed about their recruitment experiences. We also included family members of currently critically ill patients to assess current experiences ($n = 4$). Interviews were audio-recorded and transcribed. Investigators used thematic analysis to identify factors influencing family members' decisions. Transcripts were co-reviewed to synthesize codes and themes.

**Results.** Three factors influencing participants' decisions were identified: Altruism, Research Experience, and Enhanced Resources. Altruism and Research Experience described intrinsic characteristics that are less amenable to strategies for improving participation rates. Enhanced Resources reflects families' desires for increased access to information and logistical and emotional support.

**Conclusion.** Family members found their recruitment experiences to be positive when staff were knowledgeable about the ICU, sensitive to the stressful circumstances, and conveyed a caring attitude. By training research staff to be supportive of families' emotional needs and need for logistical knowledge about the ICU, recruitment of a potentially more diverse sample of families may be enhanced. J Pain Symptom Manage 2017;■:■–■. *© 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

***Key Words***
*Critical care, palliative care, research recruitment, ethics, qualitative methods*

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## *Context*

The generalizability of palliative care research in the intensive care unit (ICU) setting is often constrained by low participation by patients and family members. Because critically ill patients frequently lack decision-making capacity, consent and participation in research often falls to patients' families.[1–5] Sending surveys to family members after the death of a patient is a common method for collecting data regarding the quality of palliative care. A previous study demonstrated systematic differences between patients whose family members completed surveys after a patient's death in the ICU and those who did not.[6] Importantly, patients with a participating family member were more

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All authors made substantial contributions to the design of the work or the acquisition, analysis, or interpretation of the data; participated in revising it critically; provided final approval of the version to be published; and agree to be accountable for the work.

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likely to have received elements of palliative care.[6] In addition, family members of patients who completed a post-death survey were more likely to be white, married, and older than family members who did not complete a post-death survey. These differences may threaten the validity of palliative care research with family members and raise ethical questions about the potential for worsening disparities in care by failing to adequately represent diverse perspectives. This study's primary aims were to explore: 1) barriers and facilitators that influenced families of patients with critical illness to participate in research about palliative care and 2) potential methods to enhance participation of these families in this research.

## *Methods*

### *Study Design*

This study is a supplement to the Family Communication Study (FCS), a randomized trial testing the efficacy of a communication facilitator for improving the quality of communication between ICU clinicians and families of critically ill patients.[7] FCS was conducted at two hospitals in the Pacific Northwest. The objective of the trial was to determine if a facilitator focused on improving clinician-family communication in the ICU reduced family member distress and intensity of end-of-life care for patients. Patients were randomized to usual care or a communication facilitator. Of 352 family members eligible for FCS, 269 participated (76%).[7] This intervention focused on improving clinician-family communication and primary palliative care.

### *Sample and Data Collection*

A convenience sample of family members was collected for this study. Family members were recruited from three groups: 1) those who participated in FCS; 2) those who declined participation in FCS; and 3) family members with patients currently in an ICU (Table 1). Although this study was initially designed to interview family members from Groups 1 and 2 only, we found many of the families from Group 2 reported limited or no recollection of being recruited to FCS. Despite these families' inability to remember previously being approached to participate, we felt that insights based on their *current* thoughts about being asked to participate in research were nonetheless valuable, and we included them in the interviews. We also recruited family members with patients currently in the ICU with the goal of having them provide real-time reflections on being recruited to critical care research (Group 3). Family members in Group 3 were recruited from ICU waiting rooms with the assistance of hospital staff members who identified family members who would be available for recruitment in the waiting room (Table 2).

Semi-structured interviews were conducted over the telephone ($n = 20$) or in person ($n = 5$). One author (D. D) conducted interviews from January 2012 to July 2012 (Appendix). Family members were asked to discuss their experiences and opinions about study recruitment and to describe their reasons for agreeing or declining to participate in research at the time their loved one was in the ICU.

The Human Subjects Division of the University of Washington approved both the FCS study and this additional study.

### *Analysis*

Interviews were recorded, transcribed, and analyzed using a thematic analytic approach that included coding and thematic synthesis.[8,9] Interview transcripts were analyzed using the data analysis software "dedoose" (dedoose.com, versions 5.1.20–5.2.0). One author (D. D.) conducted the initial coding of all transcripts with the goal of developing preliminary codes. A second author (E. N.) independently reviewed transcripts, confirming or revising existing codes, as well as creating new codes. All transcripts were then co-reviewed (D. D., E. N.), reconciling any differences and refining code definitions. Lastly, codes were analyzed, integrated, and synthesized into themes by all authors. For potential solutions to barriers to family member recruitment, we included solutions directly

*Table 1*
**Recruitment Rates**

| Outcome | A. Group 1: FCS Participants ($n = 42$) | B. Group 2: FCS Refusals ($n = 48$) | C. Group 3: ICU Waiting Room ($n = 4$) |
|---|---|---|---|
| Contacted | 38 | 38 | 4 |
| Completed interviews | 14 | 7 | 4 |
| Unreachable | 4 | 10 | N/A |

FCS = Family Communication Study; ICU = intensive care unit.

*Table 2*
**Participant Demographics ($n = 25$)**

| | |
|---|---|
| Age (Mean, SD)[a] | 53 (12.4) |
| #Female, % | 19 (76) |
| #Relationship to patient (%) | |
| Parent | 10 (40) |
| Child | 7 (28) |
| Spouse or partner | 4 (16) |
| Sibling | 3 (12) |
| Other relative | 1 (4) |
| #Race, %[a] | |
| White | 21 (91) |
| American Indian/Alaska Native | 1 (4) |
| More than one race | 1 (4) |
| #Ethnicity, %[a] | |
| Non-Hispanic | 23 (100) |

[a] Age, race, and ethnicity were not collected from two participants ($n = 23$).