Being There: Inpatients' Perceptions of Family Presence During Resuscitation and Invasive Cardiac Procedures

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Background Although patients' families want to be invited to the bedside of hospitalized loved ones during crisis events, little is known about patients' perceptions of family presence.

Objective To explore adult inpatients' perceptions of family presence during resuscitation, near-resuscitation, and unplanned invasive cardiac procedures shortly after the life-threatening event.

Methods In this qualitative study, data were collected by interviews at least 13 hours after a crisis event and before hospital discharge. Data were audio recorded, transcribed, and analyzed for themes.

Results From the bedside interviews (N=48), the overarching theme of "being there" was explained more specifically as "being there is beneficial," "being there is hard," "families in the way," and "desire for control." Most participants preferred family presence, although preferences varied with types of crisis events, patients' predictions of family members' responses, and the nature of family relationships. New perspectives emerged about patients' decision making related to family presence.

Conclusions This study extends existing knowledge about factors that influence the decision-making processes of hospitalized patients regarding family presence during a crisis event. Health care professionals can provide support as patients ponder difficult decisions about who to have present and can reduce patients' fears that families might interfere with the life-saving efforts. (*American Journal of Critical Care.* 2015;24:e108-e115)

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Family-centered care calls for the integration of patients' families into patient care and decision making during hospitalization for acute and critical illness.[1,2] Evidence suggests that family presence and family engagement can improve patient safety and comfort, reduce length of hospitalization, enhance communication between patients' families and health care providers, reduce costs, and decrease readmissions.[1-7]

As patients' families spend more time at the bedside, requests to be present during crisis events increase. For example, families express not only a desire but a perceived right to be present during invasive procedures and resuscitations of loved ones.[8-13] Research reflects that families value receiving timely information in a transparent manner, comforting their loved one, and having closure when they are present during crisis events.[2,9,14-17]

Research with health professionals similarly suggests that family presence during resuscitation and invasive procedures helps families grasp the severity of life-threatening events, facilitates communication, supports grieving, allows families to see the efforts of the care team, and reduces litigation risk.[9,15,16,18-21] Health professionals also perceive disadvantages, including performance anxiety of resuscitation teams, family disruptions of care, deleterious effects on family, compromised patient confidentiality, increased litigation risk, and family's desires to prolong futile resuscitation.[9,18-20,22-25] Research findings have not supported the disadvantages perceived by health professionals[17,19,26,27]; therefore, major health organizations now encourage family presence during resuscitation.[28-36]

Minimal research exists on patients' perceptions of family presence during life-threatening events. In studies that suggested patients' preference for family presence during resuscitation and invasive procedures, data were often based on hypothetical situations or were collected weeks or months after actual life-threatening events.[11,13,15,37-40] The purpose of this study was to qualitatively explore adult inpatients' perceptions of family presence during resuscitation, near-resuscitation, and unplanned invasive cardiac procedures within hours or days of the life-threatening event. These 3 categories of events share close similarities in terms of risk of nonsurvival, and all have been understudied in research.

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Methods

The study design was exploratory-descriptive[41] and employed qualitative methods. The convenience sample consisted of alert, physiologically stable adult inpatients who had experienced life-threatening events and contributed data 13 to 96 hours after the event. Events included in-hospital resuscitations, defined as clinical conditions requiring immediate intervention by resuscitation teams, typically including chest compressions and artificial airway maintenance; in-hospital near-resuscitations, defined as clinical conditions requiring immediate intervention by emergency teams but not involving chest compressions and artificial airway maintenance; and unplanned cardiac interventions requiring hospitalization, including placement of stents, pacemakers, and internal defibrillators. In this study, "family presence" was synonymous with family presence during resuscitation and unplanned invasive cardiac procedures, defined as family members positioned so as to see their loved ones during treatment for life-threatening events.

> Research on patients' perceptions of family presence during life-threatening events is minimal.

Data were collected at Indiana University Health Ball Memorial Hospital, which did not have a policy regarding family presence during life-threatening events. Decisions about family presence during resuscitation were usually made by the health care team on a case-by-case basis, with general openness to such presence in most units. However, there was very little openness to patients' family members being present during cardiac procedures. No sampling criteria were set regarding the presence or absence of patients' families during the focal event.

Data Collection and Analysis

All inpatients who gave consent were interviewed by the same doctorally prepared member of the

Table 1
Description of the sample (N = 48)

Characteristic	No. (%)
Age, y	
21-40	4 (8)
41-60	18 (38)
61-80	15 (31)
>80	11 (23)
Sex	
Male	24 (50)
Female	24 (50)
Education	
High school	37 (77)
College	11 (23)
Ethnicity	
African American	3 (6)
White	45 (94)
Type of life-threatening event	
Unplanned cardiac procedure	23 (48)
Resuscitation	12 (25)
Near resuscitation	13 (27)
Family presence during focal event in this study	
Yes	10 (20)
No	38 (80)

research team (R.T.) because she had extensive experience in research interviewing. The initial interview question was, "Thinking of your recent life-threatening event here in the hospital, please share your thoughts on having family members present beside you as the care team intervened." The interviewer followed an interview guide with 13 possible follow-up questions and probes. Interviews were audio-recorded and transcribed verbatim. Interviews ranged from 4 to 30 minutes (mean, 14 minutes). The study was approved by 2 institutional review boards.

Through a recommended approach to thematic analysis,[41] 5 members of the research team immersed themselves independently in the transcripts, marking the text manually or by computer. After reading and rereading the data to allow prolonged engagement, each researcher identified initial codes and themes. Researchers then met and discussed individual codes and themes, comparing various schemata with the data. One team member who was experienced in qualitative analysis (C.T.) guided the discussion. The team unanimously agreed that there was saturation of the data, as no new ideas were arising from the last 10 interviews. Themes were merged until consensus was reached on 4 major themes, which were labeled with participants' own words. Decision points were recorded to create an audit trail.

Results

Respondents

The sample (N = 48) consisted of an equal number of males and females, primarily white with a high school education. Approximately half of the participants experienced an unplanned cardiac procedure, one-fourth experienced resuscitation, and one-fourth experienced near-resuscitation. Twenty percent of participants had family members with them during the life-threatening event (Table 1). Response rate was 85%. All but 1 respondent participated 13 to 96 hours after the life-threatening event.

Preferences for Family Presence During Resuscitation

More than 60% (n = 29) of the responding patients preferred family presence. Of the 19 who did not, 17 had experienced an unplanned cardiac procedure. During the interview, 5 of the 19 changed their preference and desired at least 1 family member to be present. More than 90% of the respondents who experienced resuscitations or near-resuscitations preferred family presence.

Of the 19 respondents who were negative or unsure about family presence, 10 would want to be present if the situation were reversed and they were a family member of a loved one who was being resuscitated. Two respondents' commented on their conflicting preferences:

> It would make my family too sad to watch me nearly dying. But if it were them being worked on, I would be in there. It doesn't matter if I'm sad or not.

> I guess I'm stupid, telling you that I'm not sure I want my family to be in with me, but I certainly want to be in there for them.

Nine respondents did not want family presence as a patient or a family member.

Themes

Respondents most frequently described family presence as "being there." Four themes emerged: "Being there is beneficial," "Being there is hard," "Families in the way," and "Desire for control" (Table 2).

Being There is Beneficial. Two-thirds of respondents described the importance of families being together during life-threatening events. One subtheme was family-centered benefit. Families could know "everything was done," receive timely information, experience "closure," and "cope better."

> It would have been awful for my daughter to be stuck in the hall and not know anything. Instead, she was there with me and could see everything.

> Family presence allows us all to say goodbye. No one should die alone.

A second subtheme was patient-centered benefit. Family presence was comforting to patients; patients

(n = 17) benefited when families prayed, talked to them, and kept them calm.

> It's important for my family to just be there. They don't have to do anything. We can just look over at each other . . . I knew when I saw them that I mattered to them. They hadn't forgotten or given up on me.

> I want them to be here with me, and I would be here for them. We would bring each other comfort. We would not be out in the hall!

> If I had opened my eyes to a roomful of complete strangers, it would have really scared me. Seeing my daughter's face was very comforting.

Fourteen respondents who had experienced family presence in the past as a patient or family member shared freely their positive experiences. Only 2 respondents did not prefer to be present again because of the troubling nature of the visual images. Participants suggested that nurses should be with families to explain the developments.

Being There is Hard. Respondents reported family presence was "hard," specifically "hard to watch" for families and, for patients, "hard to decide who" should be present. For the subtheme "hard to watch," participants worried about effects on families. Participants who did not prefer family presence wanted to protect families from stress. Four respondents mentioned they wanted to be remembered the way they were. Three commented that families should not be present if events were bloody or disfiguring.

Related to the subtheme "hard to decide who," the phrase "it depends" was common. Respondents' desire for family presence depended on whether or not family members would behave appropriately and knew about health care.

> My daughter is a nurse. She would be there every time. She would know when to worry and when not to.

> My oldest daughter would be trying to tell everyone what to do. It's better if she's not there.

> It depends. Some of mine would do better than others.

Relationships between patients and family members influenced patients' decisions about who should be present. All married participants (n = 24) desired spouses to be present, even if it was difficult for the spouse. Respondents who preferred family presence tended to characterize their families as "close" and wanted multiple family members present. However, at least half of respondents wanted to be selective about who was present.

> I wanted my wife with me for sure. After my wife, it got a little iffy who to have. My wife would have been there no matter what. No one could have stopped her.

> That's part of "till death us do part." You stay for the last breath.

> It depends on the relationship, if you are close or not. My mom and I are close, so we will be there for each other. And I would definitely be there if it were my child.

One-third hinted at discord in family relationships, which made it "hard to decide."

> It would never work to let some of my kids in and not others. Better to keep them all out.

> My family doesn't get along, so it would depend on who was here. It might be bad if they were all in there.

Of the 15 respondents who commented about who owned the decision, 6 thought patients should decide, often sharing how they would think through the hard decisions.

> When life hangs in the balance, it is all about the patient. Someone might get mad, but patients get to decide who is with them.

Eight believed that families should decide; only 1 respondent thought that the health team should decide because the patient and family may not fully understand a complex situation.

> It depends on a lot of things, but my family ought to decide to come in or

Table 2
Overview of results: central theme, themes, and subthemes

Central theme	Themes	Subthemes
Being there	Being there is beneficial	Family-centered benefit Patient-centered benefit
	Being there is hard	Hard for family to watch Hard for patient to decide who should be present
	Families in the way	Not enough space in hospital rooms Emotional responses of family might interrupt care team Emotional responses might disturb patient
	Patient's desire for control	Trying to predict family's responses Control how family sees me No concern over confidentiality of information

not. I may not be around afterward. No one should decide that for my family.

Families in the Way. The theme around which respondents (85%) most strongly agreed was that family members might "get in the way" of the care team. One subtheme was "not enough space in hospital rooms."

> The nurses can't care for the patient and everyone else. The team couldn't get my bleeding stopped yesterday, and they didn't have time to work around my family. If families are in the way, they need to leave. Seconds matter and could cost someone their life.

A second subtheme was that families might interrupt the care team by "asking questions," "crying," "yelling," "passing out," or becoming "emotional" and "hysterical." Participants believed emotional responses might distract the care team and divert efforts away from patients.

> Some families can't take it, and then you would have a whole bunch of "patients" in the floor, and the doctor couldn't concentrate on me!

> One wrong move and I'm a goner, so I don't want anyone in the doctor's way.

In addition, emotional family responses could upset the patient.

> They might get in my face, and I don't need that.

Desire for Control. A fourth theme mentioned by 12 respondents was a desire for control related to family presence. Respondents tried to predict out-of-control behaviors of family members, which was the first subtheme.

> God only knows what my kids might do in there.

> I only want family with me who will be OK, you know, not screaming or anything.

Five respondents wanted to control how families saw them.

> I wouldn't want anyone looking at me. It is embarrassing—degrading even. You don't even know if you are uncovered or not.

No respondents expressed concern about controlling confidentiality of information.

> During my cath, I didn't care if my sister and friend heard it all. It doesn't matter right then. You just want someone to hang on to, and you want to live through it.

Discussion

Most respondents preferred family presence and described it as "being there." Although family presence could be hard, it was perceived as holding benefits, as long as families did not get in the way and patients had desired control. Not all respondents preferred family presence, a finding consistent with other studies of hospitalized patients.[11,13,17,37,42]

Our findings paralleled those found in a qualitative study[37] of European patients, 21 of whom experienced resuscitation. Being there, ensuring the care team was uninterrupted, and concern about effects on patients' families were similar themes in both studies. Dissimilarly, in our study, perceptions differed markedly between respondents who experienced resuscitation and those with unplanned cardiac procedures. Overwhelmingly, respondents who experienced cardiac procedures did not want family presence; concerns of family being in the way during the procedure were particularly strong, with several noting the small size of the procedure room. Equally strong was the voice in favor of family presence among those experiencing resuscitations or near-resuscitations.

The most pervasive concern of respondents was that patients' families would impede the care team. Similarly, health professionals have expressed concerns about performance anxiety and family interruptions.[9,23,43,44] However, studies have not documented increased stress on the medical team or changes in care delivery.[17,45] Only 1 study's findings suggested that overtly vocal families may impede physicians' functioning during a resuscitation, which was conducted as a simulation.[22] More research is needed on this crucial aspect of family presence.[44]

Many concerns of respondents could be readily addressed through having a family facilitator during family presence. Family facilitator roles are recommended by the American Association of Critical-Care Nurses (AACN)[28] and supported by other professional guidelines.[29,30] The family facilitator role holds much promise for reducing (a) the risk of families getting in the way, (b) patients' anxiety about families' responses, and (c) families' misunderstanding of events.[28,46] The AACN Practice Alert[28] also recommends the formation of institutional policies and procedures in support of family presence (Table 3). Patients' preferences for family presence might be different and concerns might be fewer if this study were replicated at a site where family facilitators and policies are in place.

Our study, like others,[37,38] did not reveal any concerns among patients about confidentiality during family presence. Similarly, perceived benefits of family presence in our study aligned closely

Table 3
Key points of the American Association of Critical-Care Nurses (AACN) Practice Alert on Family Presence During Resuscitation and Invasive Procedures[28]: expected practice and actions for nursing practice

Expected practices	Actions for nursing practice
1. Family members of all patients undergoing resuscitation and invasive procedures should be given the option of presence at the bedside.	1. Ensure that your health care facility has written policies and procedures that support family presence during resuscitation and invasive procedures
2. All patient care units should have an approved written practice document (ie, policy, procedure, or standard of care) for presenting the option of family presence during resuscitation and invasive procedures	2. Policies and procedures and educational programs for professional staff should include the following components: • Benefits of family presence for the patient and the patient's family • Criteria for assessing the patient's family to ensure uninterrupted patient care • Role of the family facilitator in preparing families for being at the bedside and supporting them before, during, and after the event, including handling the development of untoward reactions by family members; family facilitators may include nurses, physicians, social workers, chaplains, child life specialists, respiratory therapists, and nursing students • Support for patients' or family members' decision not to have family members present • Contraindications to family presence (eg, family members who demonstrate combative or violent behaviors, uncontrolled emotional outbursts, behaviors consistent with an altered mental state from drugs or alcohol, or those suspected of abuse)
	3. Determine your unit's rate of compliance in offering patients' families the option of family presence during resuscitation and invasive procedures; if compliance is <90%, develop a plan to improve compliance: • Consider forming a multidisciplinary task force (ie, nurses, physicians, chaplains, social workers, child life specialists) or a unit core group of staff to discuss approaches to improve compliance • Re-educate staff about family presence; discuss the intervention as a component of family-centered care and evidence-based practice • Incorporate content into orientation programs as well as initial and annual competency verifications • Develop a variety of communication strategies to alert and remind staff about the family presence option
	4. Develop proficiency standards for all staff involved in family presence to ensure patient, family, and staff safety
	5. Develop documentation standards for family presence and include rationale for when family presence would not be offered

with studies of patients, patients' families, and health professionals.[9,11,15,16,18-21,37,42] No new benefits emerged from our data, confirming a growing and strong consensus about benefits.

A new perspective that our study offers is an explication of how hard family presence can be—hard for families to witness, hard for care teams if families get in the way, and especially hard for patients to decide. Participants offered rich accounts of being selective and making "hard" decisions that "depended" on many factors. Previously undescribed decision processes emerged. For example, respondents considered the nature of family relationships. Respondents who characterized families as "close" preferred family presence more strongly. Married respondents clearly preferred spousal presence. Presence by adult children sometimes created uncertainty and required deliberation, especially if family dynamics were tense. Respondents tried to predict how family members would respond and how they would be affected. They expressed perceived responsibility for inviting only persons who would not be out of control, yet reflected with tears their desire to stay connected to family during crisis. As respondents deliberated, some changed from being against family presence to being in favor. This shift occurred most commonly when respondents realized that, if they were the family member, they would want to be present.

As in other studies,[11,13,37] respondents clearly believed that patients and their families owned the decision about family presence, in contrast to published opinions of health professionals who believed that the health professionals should decide.[19,27,47-49] Family presence can be a source of moral distress for health care professionals when patients' wishes conflict with institutional policies or the preferences of other powerful voices, such as physicians.[50] After 2 decades of debate, unresolved aspects of family presence exist and require thoughtful consideration and further study.

Limitations

This single-site study had a predominately white sample. The design did not allow generalization of results. The methods did not permit an analysis of the influence of demographic variables on the results. Despite efforts to ensure rigor in the data analysis, researcher bias could have influenced the results. Finally, we do not claim to have exhausted all possible potentially identifiable themes. Only a small number of participants had family members present during the target life-threatening event; thus, although all participants had the experience of a life-threatening event, most did not have the experience of family presence.

Recommendations

Health professionals should facilitate discussions about family presence before life-threatening events, perhaps when advanced directives are reviewed. Decisions about family presence require time to process. Future research can map patients' decision-making process, perhaps through grounded theory approaches, so that health professionals can have the knowledge to anticipate and support decision making. Models for patients' decision making during crises could be developed, perhaps building on existing knowledge about patients' preferences for end-of-life care and advanced directives. More research is needed on larger samples of patients who have experienced only invasive cardiac procedures or experienced only resuscitation and survived.

Summary

These results add to a growing consensus that most hospitalized adults experiencing crisis events prefer family presence. Although "being there" can be hard, family presence holds benefits, as long as families do not impede the care team. Our study revealed new information about previously undescribed decision points that patients encounter when considering family presence. In addition, patients' preferences may vary with the nature of life-threatening events. Integrating family facilitators into family-centered care and hospital policies could alleviate decisional burdens on patients, provide support for families, and reduce anxiety among members of health care teams.

FINANCIAL DISCLOSURES
None reported.

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SEE ALSO
For more about family presence, visit the *Critical Care Nurse* Web site, **www.ccnonline.org**, and read the article by Bishop et al, "Family Presence in the Adult Burn Intensive Care Unit During Dressing Changes" (February 2013).

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