

Let Them In: Family Presence during Intensive Care Unit Procedures

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Abstract

Families have for decades advocated for full access to intensive care units (ICUs) and meaningful partnership with clinicians, resulting in gradual improvements in family access and collaboration with ICU clinicians. Despite such advances, family members in adult ICUs are still commonly asked to leave the patient's room during invasive bedside procedures, regardless of whether the patient would prefer family to be present. Physicians may be resistant to having family members at the bedside due to concerns about trainee education, medicolegal implications, possible effects on the technical quality of procedures due to distractions, and procedural sterility. Limited evidence from parallel settings does not support these concerns. Family presence during ICU procedures, when the patient and family member both desire it, fulfills the mandates of patient-centered care.

We anticipate that such inclusion will increase family engagement, improve patient and family satisfaction, and may, on the basis of studies of open visitation, pediatric ICU experience, and family presence during cardiopulmonary resuscitation, decrease psychological distress in patients and family members. We believe these goals can be achieved without compromising the quality of patient care, increasing provider burden significantly, or increasing risks of litigation. In this article, we weigh current evidence, consider historical objections to family presence at ICU procedures, and report our clinical experience with the practice. An outline for implementing family procedural presence in the ICU is also presented.

Keywords: patient family engagement; family presence; intensive care unit procedures; patient-centered care

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When Plamping repurposed the phrase “nothing about me without me” to call for full inclusion of patients in their medical care, she illuminated powerfully the basic rationale for patient-centered rather than primarily clinician-centered care (1, 2). In the intensive care unit (ICU), the “me” of that famous phrase also includes the people whom the patient wants involved in her care, individuals we call “family” here (3).

Families have sought full access to ICUs and meaningful partnership with clinicians for decades (4), resulting in improvements in family access and collaboration (5, 6). Despite such advances, families in adult ICUs are still routinely asked to leave the

patient's room during bedside procedures (7, 8). We assert that family presence during ICU procedures, when the patient and family both desire it, fulfills the mandates of patient-centered care. We anticipate that this will increase engagement and improve satisfaction and may decrease psychological distress among family members. We contend that family procedural presence can be achieved without compromising either trainee education or the quality of patient care and without increasing the risk of litigation or provider stress.

In this piece, we weigh current evidence and report our multiyear clinical experience

with the practice in Intermountain Medical Center's Shock Trauma ICU (STICU), incorporating as coauthors (J.J. and N.J.) members of our ICU Patient-Family Advisory Council with direct experience with family procedural presence.

Relevant Precedents

Historically, ICUs have not been patient centered, but early work has suggested the possibility of improving patient- and family-centered outcomes. Practices such as open visitation, family presence on rounds, family presence during resuscitation, and family

procedural presence in pediatric ICUs are precedents for family procedural presence in adult ICUs.

Open Visitation and Family Presence on Rounds

Current practice recommendations from multiple societies advocate unrestricted visitation, citing benefits such as improved communication and staff satisfaction (5, 9, 10). Elimination of even minimal visitation restrictions improves family satisfaction (11). Nevertheless, despite increasing liberalization, 90% of U.S. ICUs still reported some visitation restrictions, albeit with frequent informal exceptions (12). Beyond simple visitation, patients and families are increasingly joining ICU rounds (13), although the prevalence of such family-inclusive rounding in adult ICUs is unknown. Family-inclusive rounding appears to improve satisfaction with communication (14) and does not prolong rounding time (15).

Family Presence at Cardiopulmonary Resuscitation

Few procedures are as time-sensitive and emotionally intense as cardiopulmonary resuscitation (CPR). Robinson and colleagues (16) found that families who witnessed resuscitations (including CPR, intubations, and central line insertions) experienced no increase in immediate distress and a trend toward less post-traumatic stress. Jabre and colleagues randomized family members to an invitation to observe CPR after out-of-hospital cardiac arrest (17). Although the technical quality of resuscitation was similar between groups, family psychological distress was lower in the intervention group (17). Regardless of empirical data, family members believe they have a right to be present during CPR if they desire it (18).

Pediatric Experience

In pediatric settings, family members have formal legal and cultural reasons to mediate between clinicians and the patient, and pediatric ICUs have long included family members. Pediatric intensivists commonly accept family procedural presence (19), recognizing reduced anxiety for parents and patients with preserved procedural quality (20–22).

Patient and Family Benefits to Family Procedural Presence

Despite relevant precedents, in adult ICUs family members are often excluded from ICU procedures (23), including placement of central lines, endotracheal tubes, chest tubes, and arterial lines; CPR; lumbar puncture; paracentesis; and thoracentesis. We discuss the anticipated benefits of family presence here on the basis of the limited published evidence and our own experience. The benefits of procedural presence include family engagement and improved patient and family satisfaction but also relate to limiting the risk of post-intensive care syndrome (PICS), both in its patient (PICS-P) and family (PICS-F) forms, particularly in reducing psychological distress (24).

Possible Effects on PICS-P

Although PICS-P includes physical, cognitive, and psychological morbidities, psychological distress may be particularly relevant to family procedural presence. As in pediatric ICUs and our own clinical experience, patients may experience less fear and anxiety during procedures when a loved one is present. In addition, family procedural presence may help them ameliorate the delusional memories—related to physical discomfort, fear, and delirium—that likely contribute to persistent anxiety and post-traumatic stress disorder (PTSD) among survivors (25). On the basis of the suggestion that ICU diaries help fill in memory gaps and eliminate delusional memories, thereby decreasing PTSD (26), family members who have been present during invasive procedures may be able to help patients process fearful, confused memories of those procedures.

Possible Effects on PICS-F

Some physicians have expressed concern that families may be distressed by witnessing a procedural complication, although no evidence supports this concern. Family members may, on the contrary, benefit psychologically from procedural presence. Directly witnessing procedures may reassure family members that the patient is receiving attentive, respectful care, although further research on the effects of procedural presence on PICS-F is important. Empirically, family members who witnessed resuscitation efforts in one randomized trial did not experience increased distress

immediately, with a trend toward less PTSD and fewer cases of complicated grief up to 1 year (27).

Patient and Clinician Experience

An ICU survivor, J.J., reflected on family procedural presence, “When I was told I was going to have a procedure I would get very anxious and overwhelmed. I turned to my husband for moral support. My husband knows me better than anyone, so it gave me comfort that he could empathize with what I was going through. I think it adds to the spirit of the patient to have someone they trust by their side.” Her husband, N.J., echoed her sentiments. “While Joclynn was in the hospital my level of stress and discomfort was noticeably increased anytime I was not at her bedside. Would something happen while I was gone? What if doctors stop by to provide an update and I am not there? What if she wakes up? The questions would not stop until I was back in her room. When my wife was awake during procedures, I was also able to provide her with comfort and support.”

Physicians in STICU have gradually adopted the practice of allowing family procedural presence, when the patient and family member desire it (about half do), over the last 5 years. In 2012, about a year after families began to be present for central line placements supervised by the senior author, ICU management opened STICU visiting hours completely (11). The increase in family presence improved collaboration overall, making increased family procedural presence seem natural. When early experience did not suggest problems with family members (e.g., disruption of procedure or agitation due to witnessing procedure), procedure quality, or trainee experience, inclusion of family members at other ICU procedures increased. Our group has now performed an estimated 200 to 300 ICU procedures with families at the bedside. We provide further detail about our experience in the online supplement.

Potential Risks of Family Presence and Counterarguments

Despite potential benefits, many physicians are skeptical of family procedural presence

in the ICU: only 20 to 56% would allow family presence during CPR (8, 28). Acceptance of family presence at resuscitation varies by geographic region as well as clinician type and medical specialty (19, 29). Clinician concerns include trainee education, possible medicolegal consequences, quality of care, and provider stress. We discuss each in turn.

Trainee Education

The training of junior clinicians is crucial. Less-experienced providers are less welcoming of visitors (19% of residents vs. 79% of attending physicians) (30), but the effect of family procedural presence on trainees has not been studied. Trainees may worry that family members will be critical of their skills or not want a less-experienced provider performing a procedure. Regardless of family presence, trainees and supervisors share responsibility to create a safe and effective educational experience. The senior author (S.M.B.) routinely communicates a supervisory plan to the patient, the family, and the trainee on the basis of scripts (*see* online supplement) developed in collaboration with our Patient-Family Advisory Council. In our experience, neither family members nor trainees have had any issues with the teaching or debriefing activities.

Medicolegal Concerns

Some clinicians may worry that family member presence may increase the risk of litigation in the event of a procedural complication. This has not been demonstrated. When a family member is allowed to remain at the bedside, communication and transparency improve (31). In general, communication and transparency lead to improved family-team relations and decreased lawsuits (32). Considerable recent discussion about communicating medical mistakes to patients also suggests that improving communication is likely to reduce rather than increase litigation risks (33, 34).

Some states have allowed suits for distress at witnessing medical malpractice—especially when the individual is a close relative, is present when the injury occurs, and knows that the injury is occurring at the time (35–39)—whereas other states have not recognized such a cause of action (40–42). Courts have acknowledged with concern the risks to open visitation that such cases might represent (43) as well as

the difficulty in distinguishing distress at witnessing malpractice from distress deriving from the bad outcome itself (39). Successful litigation has involved clinicians' failure to respond to a family member's pleas in the setting of malpractice (e.g., delayed diagnosis or failure to treat a decompensating patient promptly) that was obvious to laypeople. Other than cases of intrapartum fetal demise, we could find no cases of such suits brought for a witnessed procedural complication. Family procedural presence in the ICU seems very unlikely to increase litigation, not least because clinicians are present with family members, whereas much of this litigation has involved clinicians not being sufficiently present.

Ensuring the safety of family members at the bedside is paramount. In a tragic case in California, an obstetrics patient's husband fainted as he helped to support her during an epidural placement; he died of subsequent intracranial hemorrhage (44). Similar cases have occasionally been described (45). Such occurrences, rare already, would likely have been prevented by encouraging family members to sit during the procedure and by screening individuals for fainting risk and excluding or chaperoning those at apparent risk for syncope.

Quality of Care and Provider Stress

The quality of patient care must remain foremost: no one should seriously advocate patient-centered improvements that increase morbidity or mortality. When surveyed, physicians worry that family presence may cause distraction and decrease procedure quality (7, 8). This concern has not been validated by the limited studies to date (17, 21) and has not been observed in our multiyear practice. Although a study of mock CPR suggested that defibrillation was delayed by an emotional outburst from a simulated family member (46), a study of actual care provided during CPR showed unchanged quality of care when family members were present (17). Future studies should investigate approaches to optimizing procedural quality when family members are present.

We suspect that something like the Hawthorne effect may apply when family members are present during procedures. For example, preparation for a procedure might be undertaken more thoroughly when a family member is looking on. Such

preparations should be standard already, but clinicians, like most people, tend to be more attentive under scrutiny (47).

Despite concerns that family member observation may increase clinician stress, having a family member present has not increased self-reported stress in staff who participated in witnessed resuscitation efforts (17, 48), although clinician outcomes at 1 year were not assessed (27). In our ICU, we have informally observed improvements in patient comfort and greater collaboration with family members.

Sterility Concerns

Data on sterility considerations are limited: family presence has been associated with environmental microbial contamination but not infectious complications (49). This is consistent with other sterile procedures, such as cesarean sections, which allow family members to be present in the operating room. In our multiyear experience with the practice, no family members have contaminated the procedural field; all wear a surgical mask and cap.

Future Study

Family presence at in-hospital births was adopted without much formal study as an important cultural change, and we believe that family procedural presence in the ICU, when patient and family member desire it, could be undertaken on similar terms. However, best methods to optimize procedural safety and best maximize communication and support, which orientation scripts work best, and how to optimize trainee physician experience are all important targets for study (3).

Let Them In: Recommendations for Implementing Family Procedural Presence

We recommend the establishment of policies and protocols within ICUs to encourage family procedural presence, where it is safe and desired by both patient and family. Such policies might require a "care and system redesign" approach in some settings. We propose four recommendations on the basis of multiyear experience in our adult, mixed medical-surgical ICU, incorporating the perspective



Figure 1. Comfort tent for central venous catheter placement.

of physicians, nurses, patients, and family members.

1. Educate Clinicians about Benefits to Patient and Families

Educating clinicians regarding the probable benefits to patients and family members as well as the lack of medical complications should increase providers' level of comfort about inviting and allowing family members to be present for procedures (50). A checklist (see online supplement) for deciding whether to invite family members to stay and how to prepare for the procedure could be used. At institutions where such is believed necessary, a brief waiver or similar consent document could be signed by family members for procedural presence as part of the checklist.

2. Invite Family Members to Stay, if They Desire It, As Part of Procedural Preparation

After asking the patient's permission, inviting family to stay if they want to should be part of procedural preparation; it is easily accomplished during the informed consent conversation. In our experience, about half of family members accept the invitation. As per our checklist, family members are asked about a history of

fainting or discomfort with needles or medical procedures and are invited to sit, with surgical mask and cap, shielded from potential body fluid exposures. In the rare circumstance that the medical team believed a family member might compromise procedural safety (e.g., if the family member is inebriated or psychotic), staff would ask the family member to wait in the waiting room. (This has not occurred in our experience but remains a possibility that clinicians may encounter.)

3. Consider Incorporating Family Members into the Procedure, Where Safe and Desired

All team members should be introduced to the family member and their role in the procedure explained. In our own practice, family partners often provide calming reassurance to the patient during central line placement, under the tented drape contralateral to the instrumented side. Figure 1 displays a staged example of this "comfort tent," which in our experience also decreases patients' claustrophobia (see also online supplement).

4. Engage Further

We routinely debrief trainees after procedures, discussing complications that

occurred or what the trainee could have done differently to improve the technical elements of the procedure. It would be straightforward to include debriefing of patients and family members after procedures in this process. Feedback from the patient and family member as to what information or care made them feel comfortable or helped them to understand the procedure and what might have made it a better experience for them could assist continuous quality improvement.

Conclusions

Family procedural presence in the ICU, when patient and family member desire it, should be encouraged and incorporated into the routine practice of adult ICU care. Further research about how to best implement this and other family- and patient-centered care interventions is indicated. ■

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