Published in final edited form as:

Am J Crit Care. 2018 January ; 27(1): 52–58. doi:10.4037/ajcc2018353.

Nurses' Reflections on Benefits and Challenges of Implementing Family-Centered Care in Pediatric Intensive Care Units

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Abstract

Background—Family-centered care is a proposed way of supporting family involvement with a child's care and decreasing distress associated with a child's critical illness by improving communication, helping manage stress and coping, and decreasing conflicts. Nurses are critical to successful implementation of family-centered care.

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Objectives—To describe nurses' perceptions of the benefits and challenges of providing family-centered care in pediatric intensive care units.

Methods—Semistructured interviews of 10 bedside and charge nurses in pediatric, cardiac, and neonatal intensive care units. Questions were related to 4 domains: the intensive care unit environment and its relationship to the structure and delivery of critical care, stressors for nurses and families, communication challenges and strategies, and involvement of families in care and decision-making.

Results—The main thematic finding was the nurses' descriptions of a "balancing act" to provide quality family-centered care. The balancing act was characterized by the interaction between 2 types of changes: (1) intensive care unit policies related to visitation hours and family presence at the bedside and (2) physical transformations in the intensive care unit from shared open space to individual private rooms.

Conclusions—All of the nurses viewed the transition to family-centered care as having benefits for families. They also described how changes had created new challenges for the delivery of nursing care in intensive care units, particularly regarding mentorship and the safety of patients and staff.

The pediatric intensive care unit (PICU) is a stressful environment that places considerable demands on patients and their families and can have negative effects on their short- and long-term psychosocial outcomes.¹⁻⁴ The medical complexity and seriousness of the child's illness can be overwhelming for patients' families and providers.⁵⁻⁸ A shift to family-centered care (FCC) has been proposed as a way to support the family's involvement with their child and decrease some of the distress by improving communication, helping manage stress and coping, and decreasing conflicts.⁹⁻¹⁵

Changes to support FCC include alterations of the physical environment and modifications of policies and clinical interactions. Historically, parents were allowed to visit their child in the PICU only briefly because of concern for infection control, privacy, and space. However, when research indicated that children were less stressed and were comforted by having their parents present at the bedside,⁸ policy changes allowed longer family visits, including 24-hour access. Changes in the physical environment included transitions from open floor plans to individual private rooms.

Nurses are critical to successful implementation of family-centered care.

Nurses play a critical role in the successful implementation of FCC. They are often the first point of contact for patients' families and are a consistent presence at the bedside, which allows nurses to assess family members' coping abilities, emotional states, needs, and preferences for information.⁸ Nurses are advocates to ensure that the entire family's needs are met.^{8,16} They serve as educators by interpreting medical information and facilitating communication between physicians and family.¹⁷ The purpose of this study is to describe PICU nurses' perceptions of the benefits and challenges of providing FCC, given the policy and practice changes needed to facilitate FCC in PICUs.

Methods

Overview and Setting

In this study, we used the qualitative description method described by Sandelowski.¹⁸ The goal is to produce a descriptive analysis with re-presentation of data that remains near to the original data. Although description is the key feature, analytic interpretation remains appropriate and essential to this method.¹⁸ Some of the common features of qualitative description are purposeful sampling, semistructured open-ended interviews, and concurrent qualitative content analysis.^{18,19}

This analysis is part of a larger study of stressors and supports for family members of children who are in a PICU for more than 1 week.²⁰ We sought a purposeful sample of nurses with maximum variation of participant cases.²¹ This sample included nurses from the PICU, cardiac ICU (CICU), and neonatal ICU (NICU) in an urban children's hospital. We used this sampling strategy to ensure representation from the 3 ICUs and to include nurses with a range of years of experience and responsibilities (eg, bedside or charge nurse). The authors anticipated that a sample of nurses varying in these particular characteristics would provide a range of perspectives that could be important for analysis.^{22,23} All participants in this study received a \$20 gift card. The hospital's institutional review board granted ethical approval for the study.

Data Collection and Analysis

We conducted the 1-time semistructured interviews by using an interview guide with questions in 4 domains of interest to the main study: the ICU environment and its relationship to the structure and delivery of critical care, stressors for nurses and families, communication challenges and strategies, and involvement of families in the care and decision-making processes. We made audio recordings of all interviews, which lasted between 30 and 60 minutes. Interview audio recordings were professionally transcribed verbatim and verified by the interviewer for accuracy.²¹

Qualitative content analysis is a primary analytic approach in qualitative description studies. We elected to use conventional content analysis as described by Hsieh and Shannon²⁴ because the lack of existing publications specific to nurses' experience with FCC precluded the use of a priori codes. A 4-member analysis team (E.B., H.S., A.D., and N.O.) reviewed the transcripts. Analysis began with all 4 team members independently reading and coding 2 of the transcripts to develop a coding scheme. Team members compared and consolidated the preliminary codes and entered them, along with definitions for each code, into a qualitative data management program (Dedoose; SocioCultural Research Consultants, LLC). E.B. then coded the remaining 8 interviews, which 1 other team member also reviewed. Agreement about the coding was consistently greater than 80%.

Following this initial coding, the team compared responses from the participants and identified themes that characterized the main topics across the 4 domains of interest. To gain new insights and to develop categories inductively, we looked for connections, overlaps, and contrasts between data elements and codes.²⁴ Later in the analysis, we grouped, synthesized, and consolidated categories to form themes that encompassed major related concepts. We

compared similarities and differences in participant characteristics within and between themes. We discussed these themes and example quotes in team meetings and synthesized them into 2 separate but related themes, reported in the Results.

Results

Participants

Ten nurses volunteered and completed interviews. Reflecting the composition of nurses working in the ICUs, the nurses were all women and had 1 to 39 years of experience (mean, 20 years; SD, 14.25 years). Four worked in the PICU, 3 worked in the CICU, and 3 worked in the NICU. Three (1 from each unit) were charge nurses.

Themes

All of the nurses viewed the transition to FCC and the associated changes in the physical and policy environments as having benefits for families. However, all of the nurses also described how changes had created new challenges for the delivery of nursing care in PICUs. Overall, the nurses described these benefits and challenges to providing quality FCC as a “balancing act” that was characterized by the interaction between 2 types of changes: (1) ICU policies related to visitation hours and family presence at the bedside and (2) transformation of the physical ICU environment from a shared open space to individual private rooms. The Table provides an overview of these 2 themes. Details regarding the benefits and challenges of these changes are described in the following paragraphs with exemplar quotes. The quoted speakers are identified by ICU and years of experience.

Nurses saw family-centered care as having benefits for families and creating new challenges for nurses.

Change in ICU Policy: 24-Hour Visitation

Recent policy changes allow families to be present 24 hours a day with their child. This increased bedside presence has created opportunities for parents to provide hands-on care and receive real-time information about their child’s medical condition. These changes have provided both benefits and challenges for nurses caring for the child in the complex PICU environment.

It’s good for [the families] to be there all the time, [so the child can] hear their voices, talk to them, which is great, but it does make it more difficult for us. We have so much technology to deal with, like a code happens and just the hustle and bustle of the ICU. I think it’s trying to balance that. (NICU-3, 1 year)

Benefits—Having families constantly at the bedside gave nurses more opportunities to build relationships and trust and to include families in their child’s care. Nurses reported giving family members “little jobs” such as changing diapers, giving the child a bath, or helping in certain procedures, which gave family members some control, allowed them to assume parental roles again, and “put a little more normalcy into their life.” It also showed parents that the nurses were trustworthy and allowed them to feel it was safe to leave the bedside.

This constant family presence allowed nurses to get to know families better, including their background, their understanding of their child's medical condition, and their preferences for care. It also created more opportunities to attend to the family's needs as well as their child's. For example, 1 nurse spoke of providing "simple acts of kindness" to families:

When a family's really exhausted, and they've passed out on the back couch, and they don't have a pillow or a blanket, if you stop what you're doing, and go and get them a pillow and a warm blanket, that makes a huge difference. Some of them are shocked. They are like, "Thank you so much," a simple act of kindness for a family does a lot to establish trust in the relationship. (CICU-1, 30 years)

Challenges—The nurses also reported that having the family at the bedside 24 hours a day could be "distracting" and "exhausting," especially when families asked a lot of questions when the nurse was in the middle of providing hands-on care to a critically ill child. Family presence meant dividing their attention between the child and family, which was part of the balancing act when the nurse needed to focus on the child. As 1 nurse explained, "[The parents are] just talking nonstop and needing to know every little thing that you're doing. You can be just stressful busy and they are asking questions nonstop. It's a disruption when you're trying to think of what you're supposed to do" (PICU-1, 34 years).

Nurses also spoke about the culture shift toward FCC in which families are empowered to be more directive in their child's care and have more say in how things are done. One nurse described the concern of how "nurses can be fired now by families" on the basis of different styles of nursing care.

If a nurse does something a specific way, just because that's her routine and that's her way of doing it, but it comes across to the parents that's the way it's supposed to be done, and then another nurse does it definitely a right way but a different way, then that can be hard for the families. Also with families whose kids are chronic and have been here a really long time and they have their way at home or doing things, they'll be really aggressive if you don't do it the way they do it at home. (PICU-4, 5 years)

The culture shift embraces a customer-service approach that can create conflicts with the nurses' sense of their purpose and mission, which they understand to be caring primarily for critically ill children. Although they want to accommodate families' needs and preferences, the nurses' first commitment is to ensuring high-quality patient care. One nurse spoke about this issue:

I think medicine has kind of moved away to where we're trying to be like every other profession. I feel like [the families are] basically going to Nordstrom's and expect a certain level of service versus coming to the hospital for care. This isn't about how comfortable you are here. It's about how well we can get your baby and then you go home. It's not so you can hang out here and be like, "Oh, I loved it. I have luxuries of home here." [Chuckles.] ... I say that at some point I'm gonna walk around with a little tip jar and say, "Tip me for how well you think I did today." I mean every single ounce of it is customer service, so that, I think, is killing my love for nursing, because I do love the aspect of critical thinking and

saving a life, obviously. You can't beat that, but customer service—that is not what I went in here for. (PICU-2, 10 years)

Nurses also felt the pressure of being constantly observed by families and not being able to do a thorough handoff to the next nurse at shift change if the family was present at bedside. This sometimes meant having to make extra time to find a private place and leave the room to share information.

It's so family-[focused] care now to be almost extreme and the nurses are like, what about nursing care? We don't get our half-hour to shift change anymore ... a parent never has to leave now. Never.... We really need that [time] from 7:00 to 7:30 change of shift to talk not in front of [the parents]. (NICU-1, 21 years)

Changes in the Physical ICU Environment

During the study period, the ICUs at the urban children's hospital underwent a transition in which the physical space was redesigned from a single open, multiple-bed room where nurses worked side by side to individual patient rooms where nurses now work alone with each patient and family. The nurses in this study, with a wide range of years in practice, described how neither the shared nor private space created the perfect environment for delivering FCC.

Benefits—Individual rooms reduce the rate of patient infection, decrease stressful stimuli, and provide privacy and space for patients and their families. One nurse described the transition from the previous open design to the individual room:

The peds ICU looked entirely different and was one big, open room basically with beds coming out, radiating out from a center place. It was very noisy. No privacy at all. Rocking chair hit rocking chair.... The only way you had a single room was if you needed isolation for something. When this unit opened up and [we] moved in here, it was entirely different and you had to get used to the single rooms. (NICU-2, 26 years)

Family privacy was described as one of the significant benefits of individual rooms, “where [the parents] can be with their child,” “sleep in the room,” and “do things such as breastfeed in the room.”

Challenges—Although the private rooms increased protection from infection and provided privacy for families, they created different issues regarding patient safety, particularly when nurses needed extra help. In the open environment, nurses were able to see and hear all of the patients, monitor multiple patients at the same time, and provide backup for other nurses.

From a nursing point of view, I think there were a lot of pros to having it open. One of them was just plain old backup. There was always someone who could help you with something. There was always someone who could answer a question. There was always someone who could watch one kid while your other kid was needing something. There was always someone there. (PICU-3, 39 years)

Another advantage of the open environment was the opportunity for experienced nurses to mentor their junior colleagues because they could watch them work and give them immediate feedback. Nurses with less experience were able to learn more than just the task-oriented skills by seeing nurses with more experience interact with patients' families, demonstrating the finesse that is sometimes needed to communicate well with families.

There are huge benefits [to the open room]. When you're trying to mentor people—it's very difficult to teach young people and to give them enough experiences in the situation we have now.... You had a more experienced nurse working right next to you and they might be doin' somethin' you never thought of doing, that doesn't get learned. That's the kind of thing you need to mentor. All these young people are learning how to take care of a patient and turn 'em, move around and stuff like that, but they're not learning [what] to think and say. (PICU-1, 34 years)

With individual rooms, both patients and nurses were isolated, so nurses monitoring multiple rooms could not see more than 1 patient at the same time. In addition, nurses could not hear alarms for the patient in the room next door and therefore needed to go back and forth between rooms. The nurses also commented that some parents who became accustomed to the individualized attention objected to having their child left alone. This increased the parents' feelings that they needed to stay at the bedside around the clock because they knew the nurse would be busy at times in the other room with another patient.

An open, multibed room offers huge benefits when you're trying to mentor nurses.

Additionally, nurses commented that they sometimes worried about their own safety when they were alone with family members who were upset, hostile, or behaving inappropriately. Because no one else was watching, they felt they had no choice but to stay in the room and handle whatever came their way, even if they felt threatened.

It's a little bit threatening to be in a room with a family, especially an angry family. Some of them are physically and verbally threatening, and especially the men, towards the young nurses. I tell them [the other nurses], "If you feel threatened in any way, walk out of the room." There's lots of issues to think about when you're isolated in a room with people who are critically stressed, and then there's risk. It's risk to—they're going to take it out on somebody, and you're the person standing right there, and you are young, and you seem kind of vulnerable. (CICU-1, 30 years)

Discussion

FCC is frequently cited as an approach to care that supports the parental role and involvement of parents in the care of their child^{10,11} with beneficial effects for families, children, and health care professionals.^{12–15} The structural design and policies of PICUs have changed to implement FCC,^{9–15} and nurses play a critical role in the successful implementation of these practice changes.^{8,16}

The culture shift to FCC incorporates an orientation toward customer service that includes caring for the entire family unit, not just the child, on a 24-hour basis. This shift was

generally perceived as positive, with benefits for both families and nurses. Yet the nurses' experiences in this study highlight some of the challenges that also need to be addressed following policy and practice changes to support FCC. The nurses described their lack of skills and knowledge about how to balance caring for the critically ill child and the family at the same time in the highly complex environment of the ICU.

They felt challenged to prioritize efficient, in-the-moment, complex care for the child over the needs of family involved in the care of the child. These challenges worsened when the prognosis was more uncertain or the child's health rapidly deteriorated. In these situations, the nurses had to find a balance so they could perform the highly technical and physical tasks needed to care for a seriously ill child. Some of these challenges, which have been noted in other studies on the implementation of FCC, include clinicians' attitudes and lack of family-centered skills and knowledge.^{12–14,25}

In the current FCC environment, nurses are interacting with more parents who have their own ideas, which may have come from unreliable Internet sources. The length of time dealing with families further reduces opportunities for confidential discussion, mentoring, and nurse cohesion. These changes affect nurses' time for communication, which, ironically, adversely affects patient care.

Implications for Practice

From the perspective of these nurses, the policy and practice changes associated with supporting FCC have many positive effects, including building positive relationships and engendering trust between parents and care providers.²⁶ Highlighting the positive aspects of FCC can be included in orientation of new nurses to ICU settings in children's hospitals. However, the shift toward private rooms has several unintended consequences that should be addressed.

One way to manage these consequences is to create more opportunities to mentor junior nurses who can no longer learn through observation. Junior nurses coming into ICUs in children's hospitals may need to have a longer mentorship time to become comfortable with the increased independence of caring for children and their families in private rooms. In addition, more support systems are needed for nurses who feel vulnerable when left alone with family members who confront them about their style of practice or who exhibit more threatening behavior. The constant presence of families also creates the need for private spaces where nurses can share information at shift changes and have time to foster staff cohesion.

Conclusion

Because of nurses' central role in the provision of FCC, it is important for them to be involved in decisions on how best to implement FCC. Policy and environmental changes to implement FCC within ICUs in children's hospitals should be made with nurses' input.

Acknowledgments

FINANCIAL DISCLOSURES

Research reported in this article was supported by the following National Institutes of Health agencies: National Institute of Nursing Research, award numbers R01 NR011179 and K24 NR015340, and the National Heart, Blood, and Lung Institute, award number T32 HL125195. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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Table

Thematic categories of benefits and challenges

Theme	Benefits to families	Challenges for nurses
Policy		
24-hour visitation	Comfort for patient Family able to receive information and ask questions Family participation in patient's care Facilitation of relationship building and capacity for advocacy Family provides continuity across multiple shift changes and team turnovers	Nurses "stretched" to provide care to address the needs of seriously ill child while also attempting to attend to families' needs, stressors, and grief Families place higher importance on small acts of kindness than on complex medical care of the child
Family involvement	Family participation in rounds for discussion of patient's daily care plan Nurses able to interpret and clarify information and answer questions immediately Family as "experts" on the child can help with patient care and decision-making Allows families to have a sense of control and assume parental roles	Uncoordinated communication: multiple physicians/teams say different things to the family Family relies on nurses to explain the big picture and help reconcile different physicians' views Family input seen as driving care and procedures Disagreements over importance of child's care needs can lead to distress Nurses responsible for the child's outcomes (legal consequences)
Physical structure		
Privacy	Comfort for family and patient Nurse can discuss sensitive information at bedside with family	Nurse-to-nurse shift handoffs lack the opportunity to provide rapid technical communication Mentoring other nurses hindered by change to individual rooms; must call mentee into individual rooms to see skills/interaction with family
Patient safety	Reduces infection rates Reduces noise disruption from other patients and families	Nurse with 2 patients unable to see and hear both rooms/alarms at the same time Isolation makes it difficult for nurse to seek out help from other nurses