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Family-Centered Care in the Pediatric Intensive Care Unit

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INTRODUCTION

Patient-centered and family-centered care (PFCC) as an approach to care in adult and pediatric settings has been endorsed by major professional organizations, including the Institute of Medicine (IOM), the American College of Critical Care Medicine (ACCM), and the American Academy of Pediatrics (AAP).[1-3] In 2001, the IOM[1] made recommendations for changes to the health care system that emphasized the need for patient-centered care and the ongoing and open exchange of information between health care providers and patients. Patient-centered care was defined as care that is respectful of and responsive to individual patient preferences, needs, and values. In 2007, the ACCM[2] strongly endorsed patient-centered care as defined by the 2001 IOM report, suggesting that patient and family involvement can profoundly influence clinical decisions and patient outcomes in intensive care units. This endorsement was based on the recognition that critically ill patients are often unable to participate in health care decisions and the expressed concerns of families and other surrogates that they are often poorly informed and excluded from decision making and day-to-day care of their loved ones.

With regard to the pediatric context, the AAP defines PFCC as "an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family in the patient's life."[3] The AAP policy is based on the concept of collaboration among patients, families, physicians, nurses, and other professionals. These collaborative relationships are guided by 6 principles of PFCC (Box 1). The AAP policy grows out of recent evidence that PFCC can improve outcomes for patients, families, and health care providers, decrease health care costs, and lead to more effective use of health care resources.

In this article, some of the ways that PFCC has been operationalized in pediatric intensive care units (PICUs) are discussed. Although PFCC is intended to permeate all aspects of health care, 4 areas of pediatric critical care practice have been emphasized in the literature. These areas include (1) family visitation; (2) family-centered rounding; (3) family presence

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during invasive procedures and cardiopulmonary resuscitation (CPR); and (4) family conferences.

FAMILY VISITATION

Historically, PICUs have had restrictive visiting policies, allowing only brief visits by parents and disallowing visits by siblings or multiple family members (please see accompanying article elsewhere in this issue).[4] Concerns underlying these restrictive policies included the potential for spread of infection; breach of privacy and confidentiality, emotional trauma to patients, parents and siblings; and lack of space and staff to accommodate family. However, research on the needs of families of critically ill patients has consistently shown that families desire information, assurance from staff, and proximity to their loved ones.[5,6] Parents are the natural caregivers for their children. During their child's critical illness, much of the caregiving role of parents is transferred to health professionals, because of the complex care required. This alteration of parental role has been identified as the greatest source of stress among parents in PICUs.[7-10] Parents want to be recognized as important to their child's recovery and participate in their child's care. In response to an increasing awareness of parents' needs, many PICUs have adopted 24-hour open visiting policies. Open visitation has been viewed as a first step in promoting family presence and involvement in care.

Box 1

AAP core principles of PFCC

1. Listening to and respecting each child and their family
2. Ensuring flexibility in organizational policies, procedures, and practices
3. Sharing complete, honest, and unbiased information with patients and families
4. Providing and ensuring formal and informal support for the child and family
5. Collaborating with patients and families at all levels of health care
6. Recognizing and building on the strengths of individual children and families

Data from American Academy of Pediatrics, Committee on Hospital Care and Institute for Patient- and Family-Centered Care. Patient- and family-centered care and the pediatrician's role. Pediatrics 2012;129:394–404.

PICU environments may pose many challenges to open visitation. Environmental needs identified by parents include privacy, proximity, adequate space, control of sensory stimuli (eg, noise, lighting, smell), cleanliness, safety, facilities to care for self and others, access to their child, and the presence of people who provide professional and personal support.[11] Having a place to sleep in the hospital or PICU has been identified by parents as an important yet frequently unmet need.[12] In a study conducted before and after renovation of 2 PICUs, Smith and colleagues[8] explored the impact of providing bed space for parents in the PICU on parents' stress levels. Parents experiencing PICUs with parent bed space had less total stress and less stress related to parental role alteration than those experiencing PICUs without bed spaces. In addition to sleeping arrangements, other provisions such as meal vouchers, transportation, and daily amenities may be helpful in supporting family presence in the PICU.

Siblings of critically ill children may also experience stress during their brother's or sister's hospitalization related to parental absence, substitute caregiver arrangements, changes in daily routine, and lack of information.[13] Presence at the bedside may help siblings cope with these changes. Suggestions for facilitating visits by children in pediatric and adult intensive care units include educating nurses on developmental stages and goals, preparing parents for their well child's questions and reactions, preparing siblings for what they might see and hear through age-appropriate books and other materials, screening for infection, maintaining a child-friendly atmosphere, keeping visits brief, using appropriate language, encouraging questions, debriefing after visits, and respecting decisions not to visit.[13,14] Child life specialists are a valuable resource for assisting with sibling visitation.

Based on the available evidence, the ACCM[2] recommends that parents be allowed to visit in PICUs 24 hours per day. Siblings should be able to visit with parental approval after previsit education, and siblings of immune-compromised patients should be allowed to visit with physician approval.[2] Despite these recommendations, a recent ethnographic study[10] conducted in 1 North American PICU with a long-standing 24-hour open visitation policy found that parents are still often forced to relinquish their parental role because of staff attitudes and practices that diverge from the goal of family-centeredness. A survey of Italian PICUs[15] showed that only 12% had unrestricted visiting policies, 59% did not allow continuous presence of a parent, 76% did not allow child visitors, and 32% had no waiting room. However, 48% of these units were in the process of revising their visiting policies, suggesting a readiness for change.

FAMILY-CENTERED ROUNDS

The ACCM and the AAP recommend that attending physician rounds, case presentations, and discussions take place at the bedside of critically ill children in the presence of parents.[2,3] During rounds, parents should be given the opportunity to ask questions, clarify information, and participate in decision making. Recent studies[16-24] exploring parents' and health professionals' perceptions, attitudes, and preferences regarding parental presence on rounds, and the impact of parental presence on parent and health professional satisfaction, patient privacy, resident teaching, nursing practice, and length of rounds are generally supportive.

Potential benefits of family-centered rounds include increased opportunity for parents to give and receive information and to improve their understanding of their child's condition and treatment plan.[16-24] Other benefits for parents include support of their parental role, increased capacity to advocate for their child and participate in clinical decisions, increased transparency and trust of health professionals, and increased feelings of respect. Attending physicians have an increased opportunity to educate parents, role model communication skills to residents, and observe resident competencies. Residents have increased opportunity to gain understanding of family perspectives. Parental presence on rounds may also reduce the need for nurses to mediate physician-parent communication. Potential risks of family-centered rounds include increased parental anxiety and confusion because of misinterpretation of topics discussedon rounds, breaches in privacy and confidentiality, inhibition of difficult discussions that are medically relevant (eg, poor home care, medical errors, poor prognoses), increased duration of rounds, reduced teaching related to resident discomfort when making presentations and asking questions, and attending limitation of discussions to avoid exposing gaps in resident knowledge.

Most studies of parental presence during rounds are descriptive, consisting of direct observation of rounds and surveys or qualitative interviews with parents and staff. Most studies lack adequate controls, including only parents who are present during rounds, or comparing parents who self-select whether or not to be present during rounds.[17-20] In general, these studies suggest that families prefer to be present on rounds, residents perceive decreased teaching when families are present, and no change in length of rounds or time spent teaching.

Using a predesign and postdesign, Kleiber and colleagues[22] surveyed parents, nurses, and physicians at 1 PICU before implementation of a policy inviting parental presence on rounds and again 6 months after implementation of the policy. Parents were more likely to report daily physician contact with the new policy; nurses were less likely to feel caught in the middle between parents and physicians; all physicians perceived benefit to parents and enhanced trust. There was no increase in the length of rounds under the new policy.

Landry and colleagues[23] conducted a randomized trial comparing bedside versus conference room case presentations in a PICU. Patients who had 2 consecutive morning rounds in the presence of the same resident, attending, and parent were randomized to bedside or conference room rounds on the first study day. On the second day, the alternative was performed. Parents were more satisfied with bedside presentations, felt a greater sense of confidentiality and intimacy, and more often reported being well informed about medical tests. Residents reported no difference in satisfaction or comfort level between bedside and conference room presentations, although they reported more comfort asking and being asked questions in the conference room.

Most studies of family-centered rounding have been conducted in Western societies, and some have cautioned that the findings may not be directly applicable to all cultures.[25] In a nonrandomized prestudy and poststudy conducted in a private hospital in Pakistan, Ladak and colleagues[21] found that parents preferred family-centered rounds over traditional rounds and that patient length of stay was reduced during the family-centered rounding period. In contrast to studies of family-centered rounding from the West, in which most parent participants are mothers, most parents in Ladak and colleagues' study were fathers. These investigators point out that in Pakistani culture, mothers are the primary care providers, whereas male family members are the decision makers; hence, family-centered rounds may be experienced differently based on cultural beliefs and practices.

Educating staff about the underlying principles of PFCC and reconciling these principles with staff needs and expectations is an important step toward successful implementation of family-centered rounding.[18] In addition to educating staff, educating parents about rounding procedures in the PICU has been recognized as a way to maximize benefits and reduce risks.[17,18,20] For example, Aronson and colleagues[17] found that parents present for rounds on the first day of PICU admission, compared with those present for rounds later in the PICU stay, were less likely to understand the plan, to feel comfortable asking questions, to want bad news delivered during rounds, and more likely to have privacy concerns and to want 1 person to convey the plan after rounds. These investigators suggest that parents may need special attention on the first PICU day, such as educational tools about the purpose and process of rounds and the option of family participation.

FAMILY PRESENCE DURING CPR AND INVASIVE PROCEDURES

In 2000, the American Heart Association became the first national organization to recommend the option of family presence during CPR and other invasive procedures.[26] These guidelines prompted several studies exploring health professionals' views on family presence during CPR and invasive procedures for adult and pediatric patients in emergency departments and intensive care units.[27-33] Health professionals supporting family presence believe that witnessing CPR increases family understanding and sense of control over the situation, allows the family to see that everything was done, and increases family rapport with physicians and nurses. These health professionals also believe that when patients die during CPR, family presence facilitates grieving. Health professionals opposing family presence during CPR caution that family presence may lead to increased anxiety and fear among family members, misunderstanding of events, interference with procedures or decisions to stop CPR, violations of patient privacy, performance anxiety and distraction among health providers, increased malpractice law suits, and the need for more resources such as additional staff, space, and time.

Several factors are associated with health professionals' support or opposition to family presence during CPR and invasive procedures.[28,30,34] In general, nurses are more supportive of family presence than physicians, attending physicians more than physicians in training, and pediatricians more than physicians who care for adults. Health professionals experienced with family presence, with previous education on the topic, or who work in units with formal policies in favor of family presence are also more supportive. Some health professionals believe that family presence should be considered only for less invasive procedures. Regional differences in health professionals' attitudes have been documented across the United States, with Midwesterners more likely to favor family-witnessed CPR than professionals in other areas.[27] Differences in experience and attitudes also exist between countries. Studies from the United States, United Kingdom, and Australia suggest a growing acceptance of family presence during CPR and invasive procedures. However, a recent study from Greece reported that most physicians and nurses working in the neonatal and pediatric departments or intensive care units of 3 hospitals were not familiar with, were not educated about, did not agree with, and had no written policies on family presence.[33]

The views of parents and families regarding presence during CPR and invasive procedures are overwhelmingly supportive.[35-38] Most parents believe that their presence during their child's CPR or invasive procedure helped their child and helped them. In a nonrandomized study comparing parents who were present during their child's PICU procedure with those who were not present, Powers and Rubenstein[38] found that being present reduced parents' anxiety about the procedure but not their anxiety related to the child's condition. In a randomized study comparing relatives (including some parents) who witnessed CPR on a family member in the emergency room with those who did not, Robinson and colleagues[39] found that those who witnessed CPR had a tendency for lower degrees of intrusive thoughts, posttraumatic avoidance behavior, and symptoms of grief 3 months later. In interview studies with parents whose children have undergone CPR,[35,36] parents recommend being present during the event. Parents report that feelings of fear or anxiety are not related to witnessing the CPR but rather to the possibility that their child may not survive. Health professionals have suggested that parental presence during CPR might be most beneficial for parents of children with chronic illnesses[28]; however, parents more often prefer to be present for children who were previously healthy.[35]

Few studies have attempted to measure direct effects on the child of parental presence during invasive procedures. In a randomized crossover trial, Johnston and colleagues[40] evaluated a *Touch and Talk* intervention designed for use by mothers as a means of distracting their infant or toddler during PICU procedures. The intervention did not affect the child's physiologic stability as measured by heart rate, heart rate variability, or oxygen saturation during the procedure but did lead to shorter recovery times by a mean of 24 seconds. A qualitative study exploring how parents experienced the *Touch and Talk* intervention identified an overarching theme about the importance that mothers place on being able to comfort their child and concluded that the option of parental presence during invasive procedures supports the parental role during the PICU stay.[37]

In 2006, representatives from 18 national organizations published consensus recommendations regarding family presence during pediatric procedures and CPR (Box

2).[41] The recommendations advise that policies for family presence during procedures and CPR should include definitions of family member, what procedures are covered, who facilitates, how to prepare the family, how to escort the family, how to handle disagreements, and how to support staff. Several investigators contend that the presence of a facilitator (eg, chaplain, social worker, nurse) is essential to maximize the benefits of family presence during procedures and CPR and to maintain safety.[30,42] The facilitator invites the family to be present, stays with the family during the procedure or CPR, provides explanations and emotional support, and occasionally removes those who obstruct care.

Staff education is also a key component of family presence during invasive procedures and CPR. Pye and colleagues[43] described a simulation program in which standardized persons acting as parents and grandparents were present in the resuscitation room as CPR skills were practiced on manikins. One of the goals of the simulation was hands-on training in the support of the family during CPR. Staff comfort with parental presence increased from before to immediately after training and at 1 year after training.

Box 2

Consensus recommendations on family presence during pediatric procedures and CPR

1. Consider family presence as an option during procedures and CPR
2. Offer the option after assessing factors that could have an adverse effect
3. If not offered, document reasons why
4. Consider the health care team’s safety at all times
5. Develop written policies for family presence
6. Obtain legal review of policies
7. Educate health care professionals about family presence
8. Promote research on family presence

Data from Henderson DP, Knapp JF. Report of the National Consensus Conference on family presence during pediatric cardiopulmonary resuscitation and procedures. J Emerg Nurs 2006;32:23–9.

FAMILY CONFERENCES

Family conferences are planned meetings between family members and the interdisciplinary team of professionals caring for the patient.[2,44,45] Family conferences are considered an essential forum for shared decision making in the intensive care setting. Many critically ill patients are unable to communicate with health professionals or participate in decisions about their own care because of severity of illness, use of sedation and endotracheal intubation, and in the case of children, young age and developmental state. Relatives of critically ill adults are asked to provide information about the patients’ preferences for care based on the principle of substituted judgment. Parents of critically ill children are asked to consider what would be best for the child based on the best interest standard. Shared decision making, whether guided by the principle of substituted judgment or the best interest standard, requires mutual understanding of the patient’s diagnosis, treatment options, prognosis, preferences, values, and wishes. Such mutual understanding can potentially be achieved through family conferences.

Most research on family conferences has been conducted with relatives of critically ill adults in the context of end-of-life decision making.[45-50] These studies have identified several attributes of family conferences associated with increased satisfaction and better psychological outcomes among family members. These attributes include conducting conferences within 72 hours of intensive care admission, having a private place for meeting, providing consistent communication from all team members, allowing adequate time for families to express their concerns, expressing empathy, and providing assurance. Types of empathic statements associated with increased family satisfaction during conferences include those acknowledging the difficulty of having a critically ill loved one, of surrogate decision making, and of confronting death.[49] Types of assurances associated with increased family satisfaction include those that confirm that the patient is not abandoned and does not suffer, and explicit support for the family's end-of-life decisions.[50]

In a randomized controlled trial conducted across 22 adult intensive care units in France, Lautrette and colleagues[51] evaluated the effect of a proactive family end-of-life conference and bereavement brochure on psychological outcomes of family members. The intervention had 5 objectives for health professionals summarized by the mnemonic VALUE (Box 3). Family members in the intervention group had less posttraumatic stress, depression, and anxiety 3 months after their relative's death compared with those randomized to standard end-of-life conferences.

Michelson and colleagues[52] interviewed PICU clinicians and parents whose children died in the PICU to explore their experiences with family conferences in the context of end-of-life decision making. Clinicians indicated that family conferences provide a means for communication between clinicians and parents, communication between clinicians, and support of families. Components of the interaction considered most important by staff included providing parents with information and emotional support, and allowing parents to express their needs and concerns. Recommendations from parents included regularly scheduled conferences and use of a private room. In a survey study examining the circumstances surrounding end of life in a PICU, Garros and colleagues[53] found that more than 1 family conference was required to reach consensus about forgoing life support for about half the patients.

Box 3

The VALUE mnemonic for use by health providers during family conferences

1. Value family statements
2. Acknowledge family emotions
3. Listen to family
4. Understand the patient as a person
5. Elicit family questions

Data from Curtis JR, White DB. Practical guidance for evidence-based family conferences. Chest 2008;134:835–43; and Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives dying in the ICU. N Engl J Med 2007;156:469–78.

In addition to family conferences during a child's PICU stay, family meetings after a child's discharge or death may be beneficial to some parents. Colville and colleagues[54] conducted an exploratory randomized controlled trial to evaluate the effect of follow-up meetings on parents' psychological health after their child's PICU discharge. Although no significant differences were found between groups overall, parents who reported higher levels of stress during the PICU stay had lower rates of posttraumatic stress and depression 5 months later when offered a follow-up meeting compared with those not offered a meeting. In a series of qualitative studies conducted among parents bereaved in the PICU and pediatric intensivists,[55-57] the Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network described parents' and physicians' experiences and perspectives on follow-up meetings after a child's death. From these studies, a framework for follow-up meetings was developed, which focuses on providing information, reassurance, and an opportunity for parental feedback.[58]

SUMMARY

PFCC as an approach to care is strongly endorsed by many professional organizations. Preliminary research on the implementation of programs related to PFCC in the PICU setting generally suggests benefits to patients, families, and staff. However, more research is needed using experimental designs to further define both the benefits and risks of these practices. The development of PFCC policies and their implementation in clinical practice should reflect the needs of specific patient populations and settings, and thus requires continued input from patients, families, and staff. To reduce the possibility of creating additional stress or other adverse effects, implementation also require careful education and training.

Patient-centered communication is the ideal process through which PFCC is implemented in daily practice. As applied to pediatric critical care, the key components of patient-centered communication are: addressing the patient's and family's perspective; understanding patients and families within their psychosocial context; involving patients and families in care to the extent they desire; reaching a shared understanding of the problem and agreeing on a treatment plan; and making decisions that are based on the best clinical evidence, consistent with patient and family values, and that are feasible.[2,59,60] The PICU setting presents unique challenges to communicating effectively and providing PFCC, but research-based and practical guidance is available to enable effective communication in this and other pediatric settings.[61] Thus, the growing evidence base regarding patient-centered communication and PFCC will provide guidance for future policy and practice, potentially leading to better patient and family outcomes.

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KEY POINTS

- Patient-centered and family-centered care (PFCC) is care that is respectful and responsive to the preferences, needs, and values of patients and families.
- Efforts to implement PFCC in pediatric intensive care units (PICUs)include open visitation, family-centered rounding, family presence during invasive procedures, and family conferences.
- Research on PFCC programs in PICUs generally suggests benefits to patients, families, and staff.
- Further development of PFCC programs requires continued input from patients, families, and staff.