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TECHNICAL REPORT

Patient- and Family-Centered Care of Children in the Emergency Department

Patricia J. O'Malley, MD, Kathleen Brown, MD, Steven E. Krug, MD, and the Committee on Pediatric Emergency Medicine

ABSTRACT

Patient- and family-centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and health care professionals. Providing patient- and family-centered care to children in the emergency department setting presents many opportunities and challenges. This technical report draws on previously published policy statements and reports, reviews the current literature, and describes the present state of practice and research regarding patient- and family-centered care for children in the emergency department setting as well as some of the complexities of providing such care. This technical report has been endorsed by the Academic Pediatric Association (formerly the Ambulatory Pediatric Association), the American College of Osteopathic Emergency Physicians, the National Association of Emergency Medical Technicians, the Institute for Family-Centered Care, and the American College of Emergency Physicians. This report is also supported by the Emergency Nurses Association. *Pediatrics* 2008;122:e511–e521

INTRODUCTION

Patient- and family-centered care (PFCC) is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and health care professionals. PFCC applies to patients of all ages, and it may be practiced in any health care setting.¹ Providing PFCC to children in the emergency department (ED) setting presents many opportunities and challenges. This technical report is intended to supplement the joint policy statement of the American Academy of Pediatrics (AAP) and American College of Emergency Physicians published in 2006.² It draws on previously published AAP policy statements and reports^{3–16} and reviews current literature. The present state of practice and research regarding PFCC for children in the ED setting is described, as are some of the complexities of providing such care. Best practices from a number of acute care and nonemergency settings with implications for the care of children and families in the ED are also described. The 3 appendixes include several resources for PFCC, including potential solutions for common challenges to providing PFCC faced in the ED, a draft protocol for family-member presence during invasive procedures, and resources for promoting institutional change. This technical report has been endorsed by the Academic Pediatric Association (formerly the Ambulatory Pediatric Association), the American College of Osteopathic Emergency Physicians, the National Association of Emergency Medical Technicians, the Institute for Family-Centered Care, and the American College of Emergency Physicians. This report is also supported by the Emergency Nurses Association.

BACKGROUND

PFCC ensures the health and well-being of children and their families through a respectful patient/family-professional partnership. It honors the strengths, cultures, traditions, and expertise that all members of this partnership bring to the relationship.² PFCC embraces the following concepts: (1) we are providing care for a person, not a condition; (2) the patient is best understood in the context of his or her family, culture, values, and goals; and (3) honoring that context will result in better health care, safety, and patient satisfaction. ED health care professionals, the family, and the child team up to optimize the child's care.

The development of PFCC is well described elsewhere.^{1–3,17} The essence of PFCC is an understanding of the relationship between the patient/family and health care professionals as a partnership. In the past, the fiduciary duties of a physician toward a patient were interpreted to give the physician an implied authority and ability to

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

Key Words

patient- and family-centered care, family-centered care, family-member presence, cultural sensitivity, pediatric patient's medical home

Abbreviations

PFCC—patient- and family-centered care
ED—emergency department
AAP—American Academy of Pediatrics
IOM—Institute of Medicine
EMTALA—Emergency Medical Treatment and Active Labor Act of 1986

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determine unilaterally what is in the patient's best interests. In recent years, an understanding of the relationship as one between professional and consumer gave greater authority to the voice of the "client" (ie, patient).¹⁴ PFCC represents further evolution in understanding the physician-patient relationship, one that will undoubtedly continue to evolve. The Institute of Medicine (IOM) has identified PFCC as 1 of the 6 attributes of high-quality health care in its 2001 report *Crossing the Quality Chasm: A New Health System for the 21st Century*.¹⁸ Furthermore, the Joint Commission has incorporated a patient bill of rights and standards for patient comfort in its accreditation evaluation, as well as an acknowledgment that a patient's active involvement in his or her own care is a potent strategy for ensuring patient safety.¹⁹ In its 2006 report *Emergency Care for Children: Growing Pains*,²⁰ the IOM concluded that failure to incorporate PFCC and culturally effective care into emergency care practice "can result in multiple adverse consequences, including difficulties with informed consent, miscommunication, inadequate understanding of diagnoses and treatment by families, dissatisfaction with care, preventable morbidity and mortality, unnecessary child abuse evaluations, lower quality care, clinician bias, and ethnic disparities in prescriptions, analgesia, test ordering, and diagnostic evaluation."

PFCC relies on a model of partnership with common goals and mutual respect for the contributions of each partner. This alliance is most successful when information is shared in an unbiased and nonjudgmental manner and when the patient and family are supported in their use of that information to make their own health care decisions. The clinician can be viewed as the knowledgeable navigator who is able to describe and recommend the available options with all their benefits and shortcomings; nonetheless, it is the patient and family who must fly the plane. ED health care professionals must understand that patients and families may not always know what questions to ask or may feel an inherent inequality in the partnership because of the vulnerability brought about by their medical circumstances; this may be particularly true of emergency circumstances. In addition, the possibility exists that the patient and family may value potential risks or benefits differently from how the treating physician does. Thus, the physician's ability to share information openly is vital to good patient care. Recognizing the role of the patient and family as team members in shared decision-making and validating their concerns while providing information about potential risks and benefits are critical for the entire team to feel comfortable with the plan and to ensure good patient care.

PFCC FOR THE CHILD IN THE ED

There are significant challenges to providing PFCC for children in the ED. Overcrowding and acuity in the ED may cause delay or disruption of care, which challenges the ability of health care professionals to provide respectful and sensitive care. The lack of a previous relationship between the patient/family and ED health care professionals, as well as the acute nature of many events prompting an ED visit, can limit the ability to create an

effective partnership, and the many cultural and societal variations constituting families compound the difficulty in identifying with certainty who, in fact, is a child's legal guardian. Situations particular to the ED (such as arrival of a child by ambulance without family; the unaccompanied minor seeking care without the knowledge of his or her family; visits related to abuse or violence; time-sensitive invasive procedures, including attempted resuscitation; unanticipated critical illness, injury, or death of a child) require our most thoughtful advanced planning. Finally, reluctance on the part of health care professionals to allow family-member presence during invasive procedures or attempted resuscitation has limited family access that may be beneficial to the patient, family, and health care professional alike.

Despite these challenges, achieving excellence in provision of PFCC is possible in the ED (see Appendix 1). Communication between health care professionals in the ED and in the child's medical home^{4,5} will enhance support of PFCC in the ED. Because PFCC is, by its nature, interdisciplinary, embracing the philosophy of PFCC across disciplines often available in an ED but possibly less accessible in other practice locations (such as nursing, interpreter services, child life and social services, chaplaincy, or mental health services), it can promote patient safety, comfort, and satisfaction despite the challenges of the environment.

All aspects of emergency care can reflect the practice of PFCC, including clinical operations and patient flow, policies and practice, physical plant, and education, training, and research of staff. Although the following examples may apply in other patient care settings, they are presented here in the context of the ED.

1. Patient Flow

Patient flow that exemplifies PFCC does not limit the child's access to family members or vice versa unless the demands of evolving patient independence, need for private interview or examination, or safety of the patient, family, or staff dictate otherwise. For example, an operational patient flow that requires the parent to leave the child for registration while the child is receiving care can be made more patient and family centered with a bedside registration system. Assistance can also be provided for the single parent who arrives with an ill child in the ED driveway so that he or she can remain with the child.

2. Security and Identification of Family

For security reasons, many EDs have a policy of identifying family members with a "visitor" badge. Changing that label to read "family" is a small step that may help to reinforce the commitment to moving beyond thinking of family as visitors and truly welcoming them as partners in care of the child.

3. Family Presence

A practice that requires parents to leave a child during certain procedures, such as fracture reduction or others, because the ED health care professional judges that it would be too disturbing for parents to watch is another opportunity for change. The ED can be made more pa-

tient and family centered by allowing the patient and family members to choose for themselves whether to be present after receiving complete and unbiased information about what will happen and by supporting their decision about whether to be present. Guidelines for establishing a program of family-member presence in the ED have been published.²¹⁻²³ A sample family-member presence policy is presented as Appendix 2.

4. Interpretation Services and Communication

Because communication is a cornerstone of PFCC, timely access to professional interpreter services is essential for providing PFCC when a language or communication barrier exists. A 1996 study suggested that nearly half of patients who need interpreter services do not receive them.²⁴ Moreover, children of families with language barriers are more likely to be admitted to the hospital, have more tests ordered, and have more severe disease and are less likely to get good follow-up care²⁵; thus, evidence shows that language and communication barriers do indeed lead to lower quality of ED care. A commitment to hiring and funding professional interpreter services is a high mark of an institution's dedication to principles of PFCC. The common practice of using family members or accompanying friends as translators, particularly in the setting of unfamiliar medical terms or sensitive information, runs the risk of allowing faulty communication and may compromise patient privacy and safety as well. In addition, this practice disregards the National Standards on Culturally and Linguistically Appropriate Services. These standards elaborate on Title VI of the Civil Rights Act of 1968 (42 USC §2000), which requires that all health organizations receiving federal financial assistance ensure timely and effective interpreter services for patients.²⁶

5. Comfort Care

The routine measurement of patient pain, anxiety, and comfort as part of initial and continuing patient assessment is central to PFCC, as is the commitment to respond to identified needs for comfort with interventions such as pharmacologic and nonpharmacologic treatment, child life services,⁸ and psychosocial and spiritual support. Moreover, institution-wide commitment to these practices is urged by the IOM report on quality of care¹⁸ and sought by the Joint Commission.

6. Coordination With the Medical Home

In the emergency setting, the patient's usual health care professionals can be considered an extension of that patient's family. Not only will health care professionals from the patient's medical home be able to provide valuable information at the time of the initial evaluation, but their input is necessary to shape an appropriate disposition as well. It is likely also that the patient and family will feel more comfortable with ED care when they know that their medical home health care professionals are involved and that the ED has access to essential parts of the child's medical history. This ED/medical home communication can be supported further through electronic health records and automated health-information exchange.²⁷

7. Discharge Planning and Instructions

Standard discharge instructions can be a vehicle for PFCC when they can be customized to reflect solicited family preferences that are incorporated into the family's assumption of care at discharge and include appropriate input from and follow-up with the patient's medical home health care professional.

8. The ED Physical Plant

A physical plant that embodies PFCC will accommodate family members, including well siblings, and provide restrooms, diaper-changing space, safe and dedicated pediatric waiting areas, and simple refreshments. It should also provide children protection from the sights, sounds, and smells of emergency care of other ED patients and ensure adequate privacy on-site for sensitive interviews and for families who are experiencing grief or loss.

9. Patient and Family Input in Policies and Procedures

When new policies, practices, or physical plant changes are considered, they are more likely to reflect a PFCC philosophy if family representatives are included in the planning stages. For example, patients or family representatives have provided their input on drafts of printed materials and participated in the design of new ED facilities. They may be members of a family or teen advisory board or participate as part of an interdisciplinary team to develop and implement a policy to support families and staff when family members choose to be present during resuscitation.¹

10. Modeling PFCC in the ED

For EDs in an academic center, providing supervision and teaching to trainees at the bedside, with the active participation of the patient and family, is an opportunity to model PFCC. Curricula that include precepts of PFCC^{28,29} or use families and patients as teachers³⁰ reflect another enhancement. EDs that engage in research to examine the relationship of specific PFCC practices and short-term and long-term outcomes for both patients and health care professionals can ensure that progress made toward the goals of PFCC will continue.

CHANGING THE CULTURE OF THE ED

In many institutions, changing long-standing health care professional-centered practice to be congruent with PFCC requires an interdisciplinary paradigm shift. If there is an institutional will to change, there are ample tools available to assist in the process.³¹ An Emergency Nurses Association assessment tool³² provides guidelines for implementing change and focuses on 8 domains: (1) PFCC approach in the stated mission of the department; (2) evidence of family participation in care; (3) resources for family support; (4) practice regarding information sharing and decision-making; (5) coordination of services and continuity of care; (6) personnel practices; (7) evaluation practices; and (8) community partnerships. The assessment tool has been piloted in 9 EDs.³³

A first step in promoting change is the assessment of current practice by using the self-assessment tool and soliciting information through satisfaction surveys, follow-up telephone calls, focus groups, and/or a family advisory group. Incorporating PFCC principles into the departmental mission statement can encourage influential individuals to strive for consensus and to provide leadership for change. Evaluating existing policies and procedures in light of a PFCC model can provide the impetus to change those policies. Hospital community forums through which staff can voice their concerns and share personal experiences as patients can be effective in recruiting staff commitment to PFCC.

Increasing PFCC awareness and understanding of patient/family perspectives and needs through staff education is important in the transition to PFCC. Engaging family members to assist with this task can be a powerful strategy. Staff involvement in measuring outcomes (such as satisfaction with care) and family-member presence can help overcome reluctance to support those activities. Reinforcement of PFCC values by incorporating them into job descriptions, competency assessments, and performance evaluations can help to achieve a change in culture. Finally, working to provide a physical environment that supports and reflects PFCC provides visible confirmation of PFCC. Some tool kits and additional resources for change are provided in Appendix 3.

BENEFITS TO HEALTH CARE PROFESSIONALS

PFCC has benefited health care professionals through greater job satisfaction and less burnout on the job.³⁴ Collaboration with the patient and family can lead to a more comprehensive medical record, a better sense of the patient as a person, and a better understanding of how the patient will function at home. When parents are present for the care of their child, they can help the staff provide support to the patient, understand the patient's attempts to communicate, position the patient, reduce a need for sedatives or restraints, and provide essential medical information. This may be especially important for children with special health care needs.^{35,36}

Timely and convenient interpreter services will improve both family and ED health care professional satisfaction, improve the quality and efficiency of care, and limit otherwise unnecessary use of testing and resources.³⁷ In adult patient care settings, implementing a PFCC approach has led to improvements in patient safety, fewer medical errors, and lower cost of care.³⁸ In pediatric EDs, a PFCC design of in-process rooms with a playroom-like environment can allow for better neurologic and extremity evaluation by promoting a normal repertoire of behaviors in a more normal setting.

FUTURE DIRECTIONS

Well-designed research that establishes the effects of a PFCC approach to care of the child in the ED is limited.³⁹ The IOM report on emergency care for children²⁰ highlights the importance of PFCC and recommends that emergency medical services agencies and hospitals integrate principles of PFCC into emergency care practice.

The IOM report gathers many voices (including the Institute for Family-Centered Care, the Emergency Nurses Association, and others) calling for increased evaluation and research regarding PFCC in emergency practice. Among the issues to be examined are the following:

- Regarding PFCC:
 - long-term and short-term outcomes associated with implementing PFCC, including patient satisfaction, safety and quality of care, cost of patient care, and staff satisfaction and retention
- Regarding family-member presence:
 - long-term effects of family-member presence on patient outcomes, families, and staff
 - best methods for educating health care professionals regarding family-member presence
 - potential legal ramifications of implementing or not implementing policy on family-member presence
 - relationship of family-member presence to tissue donation or autopsy
 - relationship of family-member presence to pain management (ie, is it improved by family-member presence or, conversely, does improved pain management allow for greater staff willingness to support family-member presence?)

CONCLUSIONS

Commitment to PFCC ensures that patients'/families' experiences and perspectives guide the practice of culturally sensitive care that promotes patient dignity, comfort, and autonomy. In the ED setting, particular issues deserve specific attention. The patient and family are key decision-makers regarding the patient's medical care. The option of family-member presence should be encouraged for all aspects of ED care. Information and support should be provided to the family during interventions regardless of the family's decision to be present or not. Because communication is a cornerstone of PFCC, timely and culturally effective professional interpreter services should be available to the ED. The interdependence of child and parent, patient and family wishes for privacy, and the evolving independence of the pediatric patient should be respected. PFCC encourages collaboration along the continuum of care (prehospital, ED, hospital, and rehabilitation) and commitment to the importance of the patient's medical home. With the collaboration of patients and families, institutional policies can be developed for the provision of PFCC through environmental design, practice, and staffing. Education of ED health care professionals should include the teaching of principles of PFCC to ensure active participation by patients and families in formal medical education and so that the ED setting can provide the venue for continued evaluation and research into the benefits of PFCC.

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APPENDIX 1: CHALLENGING SITUATIONS COMMON TO THE CARE OF CHILDREN IN THE ED

1. Identifying "Family"

The Institute for Family-Centered Care defines family as:

"two or more persons who are related in any way—biologically, legally, or emotionally. Patients and families define their families. In PFCC, the definition of family, as well as the degree of the family's involvement in health care, is determined by the patient, provided that he or she is developmentally mature and competent to do so. In pediatrics, particularly with infants and young children, family members are defined by the patient's parents or guardians."⁴⁰

In the acute care setting of the ED, it is necessary to identify both a legal guardian and the primary family members who can offer support to a child and the child's parent or guardian, recognizing that those entities may not be one and the same, particularly in situations of

child protective services custody, parental custody disputes, domestic violence, sexual assault, families with nontraditional composition, or families of different language or culture. However, in the case of emancipated or mature minors or for patients with selected conditions (such as sexually transmitted infections, physical or sexual assault, or potential pregnancy), the "legal guardian" may properly be construed as the patient himself or herself. Honoring the patient's implicit or explicit identification of primary family members who can provide support is essential, even recognizing that they may be different from legal guardians. When compounded by lack of a preexisting relationship, these factors make the ED practice of PFCC complex. To be able to develop policies and implement procedures for identifying family members and legal guardians that reflect a PFCC philosophy, ED health care professionals may need access to resources such as social services, interpreters, chaplaincy, security personnel, and legal counsel. Nevertheless, in providing PFCC, we are still bound by the legal obligation to share decision-making around the care of minors with a parent or legal guardian unless specific exemptions exist, such as those mentioned previously.

2. Arrival of a Child Who Is Unattended by Family

The unaccompanied child may arrive by ambulance or in the company of a teacher, child care provider, home nurse, or bystander. Providing a surrogate such as a volunteer, child advocate, or a child life specialist to the child without family, engaging ED and outside resources to locate family members, and enabling timely reunification of family and child are important for the safety and comfort of the pediatric patient of any age. As was demonstrated during Hurricane Katrina, the issue of timely reunification is an important consideration in disaster planning.

Under the Emergency Medical Treatment and Active Labor Act of 1986 (EMTALA [42 USC §1395dd]), ED providers are required to provide a medical screening examination for any unaccompanied minor who requests examination or treatment. It also requires that the same screening be provided when requested on behalf of the patient in a circumstance under which a "prudent layperson" would perceive a need for care. In fact, if the medical screening examination process identifies an emergency condition, a minor can be examined, treated, stabilized, and even transferred to another hospital without consent ever being obtained from a parent or legal guardian.⁴¹ The implications and application of this regulation have been summarized previously.^{10,15,42} A PFCC philosophy does not alter the ED health care professional's obligation to follow guidelines for a medical screening examination required by the EMTALA.

3. Care of the Adolescent Patient

Providing PFCC to the adolescent patient requires a careful balance to respect the patient's privacy and evolving independence and to communicate with the parent or guardian. Adolescents must routinely be given an opportunity to speak privately with the health care professional without other family members or partners being

present.¹⁵ Requesting a private interview with the teen-aged patient should be framed as the need to protect the young person's dignity and privacy while ensuring that information that may be critical to his or her health will not be withheld because of concern that it may worry, anger, or alienate the parent. The health care professional should be able to assure the patient that any information so obtained will be confidential to the extent that state law permits,^{43,44} unless doing so poses a direct threat to the patient's or others' safety. Clinicians must recognize that the services that are protected and accessible for confidential access vary from state to state.

Many states allow for treatment without parental knowledge if the condition may reasonably involve transmission of sexually transmitted infection, mental illness, substance abuse, or reproductive concerns.⁴⁵ Although the EMTALA specifically states that ability to pay for care must not affect care delivered, ED health care professionals should be aware that billing notification of an ED visit may constitute a breach of the adolescent's privacy and, therefore, should make provisions to safeguard patient confidentiality, including identifying with the adolescent patient the financially responsible party to be billed. ED health care professionals should be familiar with the limitations to and obligations of providing care to the unaccompanied older pediatric patient who is seeking care without the knowledge of his or her family^{10,11,46} and should make those limits and obligations clear to the patient. It is prudent to identify a means of communicating follow-up information by mail or telephone that will be secure and confidential if that is desired by the patient. One potential means of resolving conflicting obligations to the adolescent patient and guardian is for the health care professional to facilitate communication between the adolescent patient and parent.⁴⁷ This role may include exploring with the patient the potential consequences of nondisclosure to the parent, offering to disclose information to the parent without the patient present, or mediating a conversation between the patient and parent.

4. Family-Member Presence

In the procedure-intense acute care setting of the ED, PFCC is often most tested in the area of family-member presence. In the 1980s, studies demonstrated that parents were an asset in the setting of venipuncture and other simple procedures⁴⁸⁻⁵⁰ if they had been prepared for what would happen and if they were given a role other than passive witness. This finding has been extended successfully to other more-invasive procedures, and parents have been demonstrated to be successful partners in providing sucrose to soothe an infant undergoing lumbar puncture or in calming the child who is receiving procedural sedation for laceration repair or fracture reduction with a familiar voice, story, poem, or song.⁵⁰

Although some parents would not choose to be present during resuscitation, nearly all parents surveyed by Boie et al in 1999 reported that they would want the option to choose to be present or not. Other surveys have shown similar findings.^{52,53} However, surveys of

pediatricians, ED staff, and trauma care providers have noted a reluctance to allow family members to be present during resuscitation.⁵⁴⁻⁵⁶ Providers often cite fears that it will be traumatic for the family members, that families will be disruptive, or that it may result in increased litigation. EDs that have reported their experience with family-member presence for resuscitation have noted rare instances of disruption by family members and increased acceptance by staff members once they had experience with family-member presence.^{52,57-59} Staff members at these institutions noted that the family members were often helpful to the staff, providing support to the patient, essential medical information, enhanced communication, and assistance with positioning of the patient.^{53,57,60,61} They have also reported perceived benefits to the family, including a positive effect on the grieving process when a resuscitation attempt results in death.⁶² A recently published study designed to evaluate the outcomes of a structured program of family presence during pediatric trauma team activations demonstrated no instances of family interference with medical care in 197 instances of family-member presence. The time taken for completion of key components of the trauma evaluation was not different for trauma team activations with the family present versus those without family presence. In this study, most health care professionals reported that family presence either had no effect on or improved medical decision-making (97%), institution of patient care (94%), communication among health care professionals (92%), and communication with family members (98%).⁶³ Although no studies have directly addressed the effect of family-member presence on malpractice litigation, there is reason to believe that family-member presence may actually decrease litigation by improving patient and family satisfaction.^{64,65}

Although there have been few rigorous studies to date and patient numbers in those studies have been small, there is more clinical evidence to support the benefits of family-member presence to patient, family, and health care professionals than there is for the competing concerns that family-member presence might be disruptive during procedures, might be traumatic to bereaved family members, or might result in increased litigation.⁶⁶ The Emergency Nurses Association, the American Association of Critical-Care Nurses, the National Association of Emergency Medical Technicians, and the AAP have all issued policy statements in support of offering family-member presence in emergency care.^{2,67-69} Since 2000, the American Heart Association has recommended offering the option of family-member presence during resuscitation attempts (although the 2005 Pediatric Advanced Life Support teaching materials still use an example of parents who are excluded from the resuscitation room as the model for breaking news of the death of a child).⁷⁰ Guidelines for family-member presence have also been integrated into the Advanced Pediatric Life Support, the Pediatric Emergency Medicine Resource, the Emergency Nurses Association's Trauma Nursing Core Course, and the Emergency Nursing Pediatric Course. A national consensus panel that

convened in 2005 conducted an in-depth literature review of studies examining family-member presence and recommended that family-member presence be encouraged for all aspects of ED care.⁷¹ The consensus report described criteria for support staff and for possible exclusion from family-member presence (such as threat of violence to self, staff, or patient). Benefits to patient, family, and health care professionals were detailed and included the potential to optimize medical information gathering, improve the assessment of how the patient might function at home, and enhance the understanding of the patient as a person rather than a condition. This report also noted that although many institutions' practices support family-member presence, fewer than 5% of surveyed institutions reported having a written protocol. Appendix 2 presents a draft protocol for family-member presence.

5. When the Child and Parents Disagree Regarding Treatment

Disagreements between the patient and the family present a difficult challenge to providing PFCC. When the child and parents disagree regarding a proposed treatment, the ED provider must weigh the child's ability to give or withhold assent within the context of that child's ability to understand and make reasonable decisions. A toddler cannot be deemed capable of either consent or assent and will not commonly cooperate with a laceration repair. On the other hand, a 14-year-old brought by a parent with the request for drug screening can withhold assent in such a way that it might constitute assault for the ED provider to attempt to obtain a blood sample. Such a patient may well be capable of understanding the decision to refuse. Similarly, a 10-year-old who has experienced repeated relapses of cancer may be able to understand the consequences of a refusal of further invasive treatments such as a ventriculoperitoneal shunt or central venous catheter placement. That child's withholding of assent merits serious consideration by ED staff and consultation not only with parents and the child's subspecialty care team but also potentially with the primary care physician, palliative care team, chaplaincy, hospital ethics team, or child protective services. The legal aspects of when and under what circumstances minors can refuse and consent to medical treatment remain largely unresolved and complex,^{72,73} and ED health care professionals may not be able to resolve them in any particular case without the assistance of resources outside the ED.

6. When the Family Refuses a Proposed Treatment

It is not uncommon in the acute care setting for parent and health care professional to have different opinions about the value of a particular treatment or outcome. When that happens, the child's well-being should remain the primary focus, recognizing that parents and ED health care professionals may not always agree on what constitutes the child's best interest. Remembering the parents' and child's role as team members, ED health care professionals should explore the parents' reasoning and concerns in a manner that is sensitive to that reality, particularly regarding concerns about the risk of a pro-

cedure, the pain involved, the cost, the possible infringement of religious rules, or previous negative experiences in similar settings. Because there is rarely a preexisting relationship between the family and the ED health care professional, it can be helpful to enlist the health care professional of the patient's medical home in these discussions if time permits.

Parents are generally considered free to make choices regarding medical care unless those choices place their child at substantial risk of serious complications. For instance, a parent of a febrile neonate may not allow a lumbar puncture or a bladder tap. Alternatives to the standard practice of a full sepsis workup and empiric antibiotics do exist. It is possible to consider a plan to admit and observe the well-appearing febrile infant without empiric treatment or to presumptively treat an infant with risk factors or ill appearance with the hope for an opportunity to perform a diagnostic lumbar puncture later in the course of care if the family reconsiders after consulting with others.

One of the roles of the ED health care professional is to provide parents with the risk and benefit information that will allow the family to make an informed decision, ensuring that the family understands the diagnostic burden of obtaining a sterilized cerebrospinal fluid sample or the potential risks associated with a delay in initiating antibiotics. On both sides of this negotiation, there may be resources that will support a respectful and full discussion. ED health care professionals may want to avail themselves of the resource of the medical home or a subspecialty opinion; they will also want to ensure that the family members have access to the supports on which they rely to assist them with difficult decisions, such as a family elder or faith advisor. The ED health care professional should "listen carefully and respectfully to the parents' concerns, recognizing that some parents may not use the same decision criteria as the physician and may weigh medical evidence very differently."¹² Very few medical interventions are completely without any risk, although the ED health care professional can help the family to weigh any risks in the context of the untreated conditions for which they sought care. Physician liability in these circumstances is best addressed by good documentation of discussions with the family and of the steps taken to negotiate a medically safe course. In a situation in which the ED health care professional feels that a parent's decision places the child in jeopardy, then the appropriate child protective services agency should be engaged.

If a family decides to leave the ED rather than pursue the treatment choices outlined by the ED health care professional, the ED health care professional must consider the potential consequences to the child. Some institutions specifically forbid the option of allowing the family and child to leave, even after signing a form that states that they are aware that they are leaving against medical advice when the patient is a minor. In other institutions, a form and policy on leaving against medical advice exist but are rarely invoked; instead, the practice is to negotiate an alternative that is acceptable to all and to document the attempts and reasoning used to arrive

at that negotiated agreement. If a family leaves before or without such a discussion (a category often labeled “left without being seen” or “left without completing treatment”), further communication with the family should be informed by the potential for adverse outcome to the child and may range from a simple follow-up call to the family and primary health care professional to involvement of police and child protective services (personal communication, Pediatric Emergency Medicine Database discussion list [http://listserv.brown.edu/archives/cgi-bin/wa?A0=PED-EM-L], 2007).

The time frame of an ED visit does not commonly allow for the judicial process to provide a solution, although in less time-sensitive situations, many courts have shown reluctance to require medical treatment over the objection of parents “except where immediate action is necessary or where the potential for harm is rather serious.”⁷⁴ The urgency of certain interventions, therefore, requires proactive planning for such events and a well-defined process for resolving a refusal of care, including, if needed, emergency custody.

7. Visits Related to Abuse or Violence

In situations in which the patient presentation prompts consideration of possible inflicted injury, ED health care professionals need to keep all involved parties (patient, family members, and staff) safe. Precepts of PFCC in no way reduce the obligation to report suspected abuse or neglect. However, it is important to remember that the intent of such reporting is to protect the child, a goal that most families, even abusive ones, will acknowledge. Understanding that a report of suspected abuse or neglect is filed on behalf of a child rather than against a suspected perpetrator ensures that the process is patient and family centered. ED health care professionals have no obligation and no expertise to be judge or prosecutor in such situations. However, although it is not the physician’s place to indict a parent or caregiver, it is clearly the ED health care professional’s responsibility to ensure an appropriate safety plan, which may involve hospitalization or otherwise removing the child from parental care until the child’s safety can be ensured.

8. Unanticipated Critical Event or Death

Caring for the child with unanticipated critical injury, illness, or death in the ED is one of the most difficult tasks for any ED health care professional, one that requires careful planning, training, and previous identification of resources within and outside the ED. Several important resources exist to guide planning and preparation for such an event.^{4,75,76} Having protocols and procedures in place is critical for anticipating the needs of family members, who often arrive separate from their child and in emotional disarray. Under such circumstances, immediate response from designated, trained staff who are not required for the medical management of the child but whose role is to support the family is vital. Protocols should address how the ED team is to relate to media, police, private physicians, the medical examiner, child protective services, and organ- and tissue-procurement teams. Protocols should address a plan

for safe and compassionate family-member presence and identify additional resources available to the ED, such as social service, chaplaincy, acute psychiatric services, and child life services. Space should be designated for family privacy, with adequate seating, local and long-distance telephone capability, an accessible restroom, tissues, water, and writing materials.

If family members are not able to be present with the child in the ED, conveying the information of the child’s death can be a very difficult task for an ED health care professional. Recommended bereavement guidelines⁷⁴ include: informing the family in a private location; using the child’s name; informing the family of all medical procedures performed; noting any family efforts to help or comfort the child (such as seeking medical care, giving a good medical history, providing comfort by touching the child); offering information about autopsy and tissue donation; contacting important family supports such as members of the family’s faith community; offering private or accompanied time with the child’s body; allowing for time to make meaningful mementos consonant with religious or cultural precepts; and providing a follow-up contact. For most parents, the image of their child’s body lying unattended in a hospital morgue inflicts additional pain after loss. If a medical examiner’s evaluation is not required, many EDs have found a way to keep an attendant with the child’s body until a designated funeral home can come, in that way reassuring and comforting surviving family members. The death of a child is the beginning of a lifelong condition of bereavement for parents and siblings, one on which ED health care professionals can have a profound effect.⁷⁶

APPENDIX 2: SAMPLE PROTOCOL FOR FAMILY PRESENCE IN THE ED (ADAPTED FROM MASSACHUSETTS GENERAL HOSPITAL ED POLICY)

Practice Statement

Family-member presence should be considered as an option in all phases of ED care, including invasive procedures and resuscitation efforts, unless the patient’s own wishes, demands of evolving patient independence, need for private interview or examination, or safety of the patient, family, or staff dictate otherwise. The health care team will be responsible for assessing patient and family needs and supporting the family and patient during their time in the ED, whether at the bedside or not.

Definitions

Family member: a relative or person (significant other) with an established relationship with the patient.

Invasive procedure: a procedure that involves penetration or manipulation of the body.

Resuscitation: life-sustaining or life-saving measures.
Family support facilitator: a staff member (nurse, clinical nurse specialist, physician, chaplain, paramedic, or other suitable staff member) assigned to support the psychosocial needs of the family; this person should not be needed for the immediate re-

suscitation or direct assistance with the invasive procedure.

Procedure

- Designate family support facilitator
- Assess/screen family members:
 - Determine the preference of the patient, if possible. Assess the family's perception and understanding of the clinical situation and scope of crisis, need to be with the patient, coping abilities, comfort level with medical environment, and ability to ask for help or leave the area. Consider cultural preferences.
- Exclusion criteria may include combativeness, agitation, extreme emotional instability, altered mental status, and intoxication. Families who do not wish to participate should be supported in that decision and should be supported while they are separated from the patient. If the family is not offered the option of family-member presence, the reason should be documented (eg, risk of combative or threatening behavior, extreme emotional lability, behaviors consistent with intoxication or altered mental status, disagreement among family members).
- Consult with health care team: As early as possible, inform the health care team of the family's presence. Discuss with the team the family's wish to be with the patient. Both the team and the facilitator should be in agreement and determine the appropriate time for the family to be at the patient's bedside. Departmental situations or constraints should be considered.
- Prepare family member(s): The facilitator will present the clinical situation, explaining what the family member may expect to observe during the patient's treatment. The facilitator will explain to the family that patient care is the top priority and alert them to any potential limitations on time or numbers of family members who may be present, where they may sit or stand to optimize patient contact without impeding care, and any situations in which they would be escorted out of the room and will reassure them that they may leave at any time. Family members agree to the structure of their time at the bedside.
- Escort family member(s) to the bedside: The facilitator will remain with the family at all times during the visit and explain procedures and answer questions. The family will be allowed to see, touch, and speak with the patient when possible. If the time at the bedside must be limited, the facilitator will escort family to a private room and provide clinical updates on the patient's condition. A facilitator, primary nurse, or psychiatric clinical nurse specialist will follow-up with the family.

Note that this policy should undergo institutional legal review and, when verified as part of hospital policy, be part of staff education and orientation.

APPENDIX 3: RESOURCES FOR PFCC IN EMERGENCY CARE

Emergency Medical Services for Children National Resource Center Web site (available at: <http://bolivia.hr-sa.gov/emsc>)

Emergency Nurses Association. *Position Statement: Pediatric Patient Care in the Emergency Setting*. Des Plaines, IL: Emergency Nurses Association; 2007 (available at: www.ena.org/about/position/pdfs/4592d5a3e6c04a579c09be5c3fdedadf.pdf).

Institute for Family Centered Care Web. Useful links (available at: www.familycenteredcare.org/index.html.)

Rundle AK, Carvalho M, Robinson M. *Cultural Competence in Health Care: A Practice Guide*. San Francisco, CA: Jossey-Bass; 1999

Society of Pediatric Nurses. *Family-Centered Care: Putting It Into Action—The SPN/ANA Guide to Family-Centered Care*. Pensacola, FL: Society of Pediatric Nurses; 2003 (available at: www.pedsnurses.org/component/option.com_docman/Itemid,117/task.doc_view/gid,104/)

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