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

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Patient- and family-centered care is an 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 revised 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.

abstract

INTRODUCTION

Patient- and family-centered care (PFCC) is an 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.¹ PFCC applies to patients of all ages, and it may be practiced in any health care setting.^{1,2} Providing PFCC to children in the emergency department (ED) setting presents many opportunities and challenges. Unique aspects of the ED encounter include the fact that it often represents an acute visit to an unfamiliar setting without an ongoing provider-patient relationship. This technical report is intended to supplement the joint policy statement of the American Academy of Pediatrics (AAP) and American College of Emergency Physicians,³ which was reaffirmed in October 2011 (<http://pediatrics.aappublications.org/content/129/2/e561.full>) and is consistent with its recommendations. It builds on the original technical report,⁴ reviews current literature, and draws on previously published policy statements and reports.^{2,5-23} The current 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. The 3 appendices include several resources for PFCC, including

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potential solutions for common challenges to providing PFCC faced in the ED, an outline for a protocol for family-member presence (FMP) during invasive procedures, and resources for promoting institutional change.

BACKGROUND

PFCC seeks to improve the health and well-being of pediatric patients 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.^{2,3} PFCC embraces the following concepts: (1) care is provided 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 this context will result in better health care, safety, and patient satisfaction.²⁴ PFCC in the ED reminds providers that the family often has an ongoing, long-term relationship with the child, and except in extreme instances, the child returns home to be cared for by the family and the child's medical home. ED health care professionals, the family, and the child together work to optimize the child's care.

The development of PFCC is well described elsewhere.^{1-3,25} 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 duties of a physician toward a patient were interpreted to give the physician an implied authority and ability to determine unilaterally what is in the patient's best interests. As this relationship changed and became more collaborative, patients and families have become more active participants in children's health care.² PFCC represents an evolution in understanding the health care provider-patient relationship, one that will undoubtedly continue to evolve. The Institute of Medicine

(IOM) 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*.²⁶ Furthermore, the Joint Commission provides information for hospitals to implement PFCC as well as to improve cultural competence and communication.²⁷ In its 2006 report *Emergency Care for Children: Growing Pains*,²⁸ 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 represents an evolution, and in the pediatric emergency setting a PFCC approach is the best practice for patient care.

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.² PFCC appreciates that adolescent development creates a changing dynamic, which ED clinicians are obligated to recognize. Effective communication is an essential component of a patient- and family-centered approach to care.^{2,18,27} Traditionally, physicians have held a position of respect and authority in society, and it may be difficult for some families to enter into an open conversation with physicians. Additionally, 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, which may be particularly true in emergency situations. The possibility also exists that the patient and family may value potential risks or benefits differently from how the treating provider does. Thus, the provider's ability to discuss information openly by inviting families to share their concerns is vital to good patient care.^{2,18} Recognizing the role of the patient and family as team members in shared decision-making¹⁶ 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.^{2,18}

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 contribute to delay or disruption of care, making it difficult for 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. Cultural and societal influences on varied family structures compound the difficulty in identifying with certainty who, in fact, is a child's legal guardian. Similarly, families may be unfamiliar with the various providers caring for them. Patients and families also may be unaware of their role as partners in care, and a brief ED visit poses challenges to family education. Adolescent development and care needs may lead to an ED visit without family. Additionally, situations particular to the ED (such as the arrival of a child by ambulance without family; visits related to abuse

or violence; time-sensitive invasive procedures, including attempted resuscitation; unanticipated critical illness, injury, or death of a child) require the most thoughtful advanced planning. Finally, reluctance on the part of health care professionals to allow family member presence (FMP) during invasive procedures or attempted resuscitation can limit family access that may be beneficial to the patient, family, and health care professional alike.²⁹⁻³² Appendix 1 discusses difficult situations that can occur in ED care, keeping in mind a PFCC approach.

Despite these challenges, achieving excellence in the provision of PFCC is possible in the ED. Embracing the philosophy of PFCC across disciplines (such as nursing, interpreter services, child life and social services, chaplaincy, or mental health services) can promote patient safety,¹⁷ comfort, and satisfaction²⁴ despite the challenges of the ED environment. Communication between health care professionals in the ED and in the child's medical home^{5,7} will enhance support of PFCC in the ED and improve coordination of care and continuity during transitions.²³ PFCC recognizes the integral role of the family and the importance of their involvement, input, and suggestions in the ED environment.³

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

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. The intent here is to avoid

separating parents and children. 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, such as valet parking, 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. The provision of child life services or volunteers can ease family anxiety during the visit, allowing parents time to focus on their child's needs and information given.¹⁰ One challenge to the desire to keep families and children together arises in the provision of adolescent care and the necessity of incorporating privacy and confidentiality into the ED visit. Maintaining patient flow while keeping in mind patients' desire for confidentiality and state-specific regulations for adolescent care requires sensitive advanced planning in the ED.

Experiences from disasters have emphasized the importance of keeping families together. An important element of disaster planning in the ED is the efficient triage and evaluation of multiple patients. Published guidelines from a national task force provide suggestions for incorporating PFCC into the ED during mass-casualty events and encourage advanced planning with family input.³³ Although the goal remains to keep families together, prehospital or ED providers may be faced with the necessity of separating parents and children. When this happens, communication is a challenge. Recommendations in the task force report include providing a dedicated professional for communication and using digital photography and identifying information to facilitate timely reunification.³³ Disaster planning continues to be addressed at a national level.³⁴

Security and Identification of Family

Determining who constitutes a patient's family can be difficult, especially in emergencies. Patients and their families may best make that determination. Appendix 1 lists some challenging situations for the 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 the care of the child.

Family Presence

A practice that requires parents to leave a child during certain procedures, such as fracture reduction, 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 patient- and family-centered by allowing the patient and family members to choose whether to be present after receiving complete and unbiased information from an ED health professional or team about what will happen. The ED team then should support this decision, whether or not the family chooses to be present. Guidelines for establishing a program of FMP in the ED have been published.^{20,21,35} A sample FMP protocol is presented in Appendix 2. Development of an ED policy for PFCC that includes family presence emphasizes its importance in pediatric emergency care.

Interpretation Services and Cultural 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. Interpreter services in the ED are underutilized.^{36,37} Moreover, children of families who understand

or speak languages other than English 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 care.³⁸ A commitment to hiring and funding professional interpreter services, including telephone- or virtual/video-based services for difficult-to-find language interpreters, is a best practice, demonstrating an institution's dedication to principles of PFCC. The common practice of using family members or accompanying friends as interpreters, 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.¹⁷ Title VI of the Civil Rights Act of 1968 (42 USC §2000) requires that all health care organizations receiving federal financial assistance ensure timely and effective interpreter services for patients.³⁹ Although the acute nature of emergency care will sometimes create circumstances in which translators are not immediately available, advance planning can minimize these occasions. Racial and ethnic disparities in the delivery of PFCC also may exist aside from language differences and have been demonstrated for healthy children⁴⁰ as well as children and youth with special health care needs.⁴¹ In 1 study, Latino families in primary care settings experienced fewer elements of family-centered care, regardless of the language used for the visit.⁴² Disparities in PFCC for Latino and African American families of children and youth with special health care needs were found for time spent with the provider as well as sensitivity to the family's values and customs.⁴¹ The disparities were greater when the family's primary language was not English.⁴¹ Elements of quality PFCC include listening carefully, explaining things in an understandable way, showing respect, and spending enough time with the patient.⁴² These characteristics are universally appreciated by all families.

Assessing Patient and Family Needs

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,¹⁰ and psychosocial and spiritual support. This comfort assessment includes the skills necessary for the complexity of evaluating and treating children with chronic conditions that have associated pain, such as sickle cell disease.⁴³ Family satisfaction is often assessed after an ED encounter, and surveys of families reveal that they prefer shared decision-making⁴⁴ and are more satisfied with a PFCC approach.^{44,45} The challenge for providers lies in the provision of evidence-based care while involving the patient and family in the process of shared decision-making, including their values and preferences in the overall plan.⁴⁶ Responding to family needs and issues that occur during an ED visit is another aspect of PFCC, and moreover, institution-wide commitment to these practices is urged by the IOM report on quality of care²⁶ and sought by the Joint Commission.⁴⁷

Coordination With the Medical Home

In the emergency setting, it is important to include the patient's usual health care professionals as members of the ED care team, which also includes the family and ED providers. 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 may also be helpful in shaping an appropriate disposition and follow-up care plan. The patient and family also likely 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. The medical home may also have provided the family with a care plan for the patient's condition, outlining what to do when the patient is sick, including common problems and comfort measures.⁴⁸ ED providers can use these care plans during the ED visit and when communicating with the medical home. Furthermore, discussion with the medical home provider can help identify community resources or needs of the family caregivers themselves and respond to new issues (medical or psychosocial) that may arise as a result of the current ED visit. This ED-medical home communication can be supported further through electronic health records and automated health information exchange.⁴⁹

The partnership between the ED and a patient's medical home is of utmost importance when treating children and youth with special health care needs, who often have complex needs, require coordination of care between multiple subspecialists, and may have technological needs to allow proper care once they return home.⁵⁰ Children with chronic conditions are significantly more likely to have repeat visits to the ED and to be admitted to an inpatient hospital unit or PICU.⁵¹ Although there have been no systematic studies in children and youth with special health care needs and PFCC in the ED, there is evidence to support the association of high-quality PFCC in the primary care setting (medical home) and reduced number of nonurgent ED visits⁵² as well as hospitalizations.⁵³ The literature also suggests that failure of communication between the child's medical home and the ED provider at the outset of the child's ED visit might lead to potentially unnecessary testing and/or hospital admission.⁴⁵ An emergency information form is a helpful means of conveying important health information quickly, and ED providers can ask the family if they have a completed form for their child with

special health care needs or encourage them to complete one in partnership with their medical home team for any future emergency care needs.⁵⁴ At the end of the ED visit, ED providers may be aware of resources within the institution or community for children with complex chronic conditions, such as pediatric palliative care teams, that provide support for challenges such as complex decision-making and chronic symptom management. Communication with the medical home allows for coordination of care after discharge.

Discharge Planning and Instructions

Standard discharge instructions can be a vehicle for PFCC when they can be customized to reflect solicited family preferences and include appropriate input from and follow-up with the patient's medical home.¹⁷ Tools are available online to enhance communication between patients and providers, encouraging patient health literacy with the Ask Me 3 method and provider communication with the Teach Back practice.^{55,56} The recognition that health care disparities exist,⁴⁰ particularly for racial or ethnic minority groups, allows for ED planning through case management, coordination with the medical home, and a more personalized discharge process to avoid gaps in medical care and to minimize miscommunication.

Discharge planning for children and youth with special health care needs may be more complex than for typical children, especially if the ED visit resulted in a change in chronic medications or alteration of other ongoing care in the home. Discharge planning for these children may necessitate communication with home nursing agencies, medical device companies, and/or community care coordinators. Follow-up with the primary care medical home needs to be tailored to the complexity and severity of the treated condition and the needs of the family. Enhanced use of electronic medical

record–provided patient portals between the family and the primary care medical home may be explored as potential facilitators of improved communication and more condition-appropriate and compliant follow-up.

The ED Physical Plant

A physical plant that embodies PFCC will accommodate family members,² including well siblings, and provide restrooms, diaper-changing space, safe and dedicated pediatric waiting areas, and simple refreshments. ED planning can provide larger rooms for procedures and resuscitations as well as enough chairs for providers and family to incorporate family presence. It should also provide children protection from the sights, sounds, and smells of emergency care of other ED patients.⁵⁷ ED design can also provide for patient safety by reducing the transmission of infection⁵⁷ and avoiding exposure to potentially violent patients. Adequate privacy on-site can be provided with a family room for sensitive interviews and for families who are experiencing grief or loss. Availability of age-appropriate toys, books, and/or electronic media can keep both patients and family occupied during the ED visit and may decrease patient anxiety.¹⁰ 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 comfortable setting. Media sources may also present an opportunity for patient safety education including injury and disease prevention education. ED signage and education materials that are culturally and linguistically appropriate also promote a PFCC environment.³⁹

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.² For example, patients or family representatives have provided their input on drafts of printed materials and participated in the design of new ED facilities.¹ 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 Family input may be invaluable when addressing recognized problems, including disparities in the provision of care associated with the patient's or family's membership in certain ethnic or racial minority groups and in the coordination of care for children and youth with special health care needs. Families of different backgrounds can instill a better understanding of cultural differences to an institution and its staff as well as an awareness of how differences in care can result from judgments or assumptions about a patient's background or ability. Parents of children and youth with special health care needs can bring particularly helpful input to advisory boards, because their children have typically experienced more ED visits and more hospital admissions than average.⁵⁸ Additionally, the experience of these families can provide excellent education and feedback to trainees/staff teaching them a more patient- and family-centered approach. Many EDs use comment cards or postvisit satisfaction surveys to solicit feedback from families regarding the ED visit.

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. The use of photographs identifying the care team and their

roles may improve recognition, acceptance of trainees, and satisfaction with care.⁵⁹ Modeling a PFCC approach can also be accomplished through family-centered rounds^{2,60} at change of shift or by having all team members meet the patient and family together for the initial patient assessment. (Pasmann, Nelson; unpublished abstract, April 2013) In the inpatient setting, the care team approach and family-centered rounds were associated with improved family satisfaction, and families felt more involved in developing the care plan.⁶⁰ This opportunity for ED providers and staff to model PFCC extends not only to trainees within the ED but also to consulting services and their trainees from outside the ED. Role modeling has been described as a useful educational strategy for influencing professional behavior.⁶¹ Simulation scenarios that include family input provide an opportunity for trainee practice in a less threatening setting.¹⁸ Curricula that include precepts of PFCC^{62,63} or use families and patients as teachers⁶⁴ reflect another enhancement. Family participation in the identification of the dimensions of PFCC⁶⁵ and communication issues^{18,66} provides a framework for teaching these skills to trainees. Emergency care professionals who engage in research examining the relationship of specific PFCC practices and short- and long-term outcomes for both patients and health care professionals can ensure that progress made toward the goals of PFCC will continue. Moreover, there is a need for this research to include community and critical access hospitals as well as academic and tertiary medical centers.

IMPLEMENTING AN EVIDENCE-BASED PFCC PROGRAM

In many institutions, changing long-standing health care professional-centered practice to be congruent with PFCC requires an interdisciplinary paradigm shift.

Ample tools (Appendix 3) and a growing body of evidence are available to assist in the process.^{1,67-69} An Emergency Nurses Association assessment tool⁷⁰ 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.⁷¹ The implementation of a family presence program in a pediatric ED has been described using an evidence-based approach and evaluation process.⁷² This program demonstrated the feasibility of family presence without interrupting patient care.⁷²

A first step in implementation 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. Gathering evidence from supportive organizations and sharing PFCC guidelines from established programs³⁵ (Appendix 2) create a basis for an institution's own program development. 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 further promote change, and involvement of family on hospital committees lends insight into those policies that do not reflect a PFCC ideal. 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 awareness of PFCC 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 FMP can help overcome reluctance to support those activities. The reinforcement of PFCC values by incorporating them into job descriptions, competency assessments, and performance evaluations for all emergency care providers may help to achieve a change in culture, which can lead to more positive feelings among ED staff.² Trainees will learn the importance of PFCC early in their career when established providers model this approach in their practice. Finally, working to provide a physical environment that supports and reflects PFCC provides visible confirmation of PFCC. Some toolkits and additional resources for change are provided in Appendix 3.

BENEFITS TO HEALTH CARE PROFESSIONALS

PFCC has benefited health care professionals through greater job satisfaction² and less burnout on the job.⁷³ 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. Parental presence may be especially important for children with special health care needs.^{74,75}

Implementing a PFCC approach in adult patient care settings has led to

improvements in patient safety, fewer medical errors, and lower cost of care.⁷⁶ Inpatient family-centered pediatric multidisciplinary rounds have been shown to foster team collaboration and empower staff,⁷⁷ and similar team approaches have been adopted in pediatric emergency care.

FUTURE DIRECTIONS

The IOM report on emergency care for children²⁸ highlights the importance of PFCC and recommends that emergency medical services agencies and hospitals integrate principles of PFCC into emergency care practice. This same report calls for increased evaluation and research regarding PFCC in emergency practice.²⁸ More recently, it has been recommended to include patient-centered care not only during the ED visit but as part of an integrated approach to care that includes prehospital care and transitions, multidisciplinary communication, specialty consultations, and coordination with the medical home.^{24,78} Implementation of an integrated approach will require collaboration at a local and regional level, as well as the national level, to create standards for communication and coordination. The increasing role of technology creates new ways to communicate and to provide education that extend beyond the physical walls of the ED. Strategies for family involvement at all levels of medical care need to be continually explored in this evolving process. Priorities for needed research include the following:

- Regarding PFCC:
 - Long- and short-term outcomes associated with implementing PFCC in the ED, including patient satisfaction, safety and quality of care, cost of patient care, staff satisfaction and retention, reduced disparities, and improved outcomes
 - A gap analysis on the implementation of PFCC with involvement of

families and teenagers on advisory boards and committees and their impact on ED policies and procedures

- Analysis of the awareness and education of families, trainees, and staff on PFCC
- Development of a compendium of best practices for PFCC
- Evaluation of costs/savings, including changes to ED design, staffing, ED utilization, return visits, and readmissions
- Assessment of outcomes related to improved communication with the medical home
- Regarding FMP:
 - Long-term effects of FMP on patient outcomes, families, and staff
 - Development of ED policies and procedures regarding FMP and best methods for educating health care professionals, including staff training in the role of family support facilitator
 - Potential legal ramifications of implementing or not implementing policy on FMP

CONCLUSIONS

Commitment to PFCC ensures that the experiences and perspectives of patients and families guide the practice of coordinated and culturally sensitive care that promotes patient dignity, comfort, and autonomy. Role modeling PFCC is central to changing ED culture. In the ED setting, particular issues deserve specific attention. The patient and family are key decision-makers regarding the patient's medical care.¹⁶ The option of FMP should be encouraged for all aspects of ED care,³ with information and support provided to the family during interventions and as part of discharge and follow-up care planning 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,¹⁸ and efforts should be made to address health literacy during the visit and at discharge.^{55,56} PFCC respects the interdependence of child and parent, patient and family wishes for privacy, and the evolving independence of the pediatric patient. PFCC encourages collaboration along the continuum of care (prehospital, ED, hospital, and rehabilitation) and commitment to the importance of and communication with the patient's medical home.²⁴ With the collaboration of patients and families, institutional policies can be developed for the provision of PFCC through environmental design, practice, and staffing. The education of ED health care professionals should include the teaching of principles of PFCC with active participation by patients and families in formal medical education. Continued research and evaluation of the implications of PFCC in pediatric emergency practice will continue to direct the evolution of this approach to medical care and to guide our future directions.

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

Identifying “Family”

The Institute for Patient- and 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.”¹ 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. In some situations, the person consenting to medical care for the patient will be the patient himself/herself. State exceptions allow a minor to consent to medical care if he/she is emancipated,

a mature minor, or has a select medical condition.¹² Most states grant emancipated status to those who are married, economically self-supporting, or on active duty in the military.¹² Some states also recognize a mature minor status allowing certain adolescents with the ability to understand and participate in medical decision-making to consent for medical care.¹² Mature minor status is determined individually by a judge.⁷⁹ Although some courts have supported a health care provider’s decision to acknowledge mature minor status, it cannot be assumed by the ED provider.⁷⁹ State-specific statutes also may allow adolescents presenting with selected conditions (such as sexually transmitted infections, physical or sexual assault, or potential pregnancy) to consent for their own treatment.¹² It is important for the ED provider to have an understanding of his/her own state’s regulations regarding a minor’s ability to consent for medical care. 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 practice of PFCC in the ED complex. Additionally, space and privacy issues may limit how many family members can physically be present at a child’s bedside.

Once family has been identified, providers need to be aware of Health Insurance Portability and Accountability Act (HIPAA) rules protecting release of protected health information (PHI). When the patient is a child, in general, the parent or legal guardian has access to the PHI, and providers cannot release information to others without authorization.⁸⁰ However, when a minor is able to consent to his/her own medical care, either by state law or court determination, then the minor controls access to the PHI under HIPAA.⁸⁰ There are other

exceptions to the disclosure of PHI, and providers must be aware of the HIPAA rules and state-specific laws regarding confidentiality and when they apply.^{80,81} ED health care professionals need to develop policies and implement procedures for identifying family members and legal guardians that reflect a PFCC philosophy, keeping in mind issues of privacy and confidentiality. To do this, EDs may need access to resources such as social services, interpreters, chaplaincy, security personnel, and legal counsel.

Arrival of a Child Who Is Unattended by Family

The unaccompanied child may arrive by ambulance or in the company of a school official, child care provider, home nurse, or bystander. Providing a surrogate, such as a volunteer, child advocate, or a child life specialist, to the child arriving 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 unaccompanied children and need for timely reunification is an important consideration in disaster planning. A PFCC approach does not alter the ED health care professional's obligation to follow guidelines for a medical screening examination required by the Emergency Medical Treatment and Labor Act of 1986 (EMTALA [42 USC §1395dd]), and the implications and application of this regulation have been summarized previously.^{12,79}

Care of the Adolescent Patient

Providing PFCC to the adolescent patient requires a careful balance between respect for the patient's privacy and evolving independence and communication with the parent or guardian. The age at which an adolescent is considered an adult for medical decisions varies by state.

Health care providers must be aware of their state's regulations, remembering that it is a privacy violation to disclose any information protected by state law to family regardless of whether the patient is legally an adult. Adolescents prefer the opportunity to speak privately with the health care professional without other family members or partners being present.⁸² Furthermore, AAP policy recommends confidentiality in adolescent care,⁸³ and an AAP position statement declares that access to confidential health care is essential for adolescents.⁸⁴

Requesting a private interview with the adolescent 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^{85,86} unless doing so poses a direct threat to the patient's or others' safety. Health care professionals 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 consent if the condition prompting care in the ED likely falls into the categories of sexually transmitted infections, mental illness, substance abuse, or reproductive concerns.^{12,87} ED health care professionals should be aware that confidentiality concerns can occur when there is billing notification of an ED visit 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^{12,13,88} and should try to make those limits and obligations clear to the patient. It is prudent to identify a means of communicating follow-up information 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.⁸⁹ This role may include exploring with the patient any safety concerns or fears he or she may have as well as 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.

Family-Member Presence

In the procedure-intense acute care setting of the ED, PFCC is often most tested in the area of FMP. In the 1980s and 1990s, studies showed that parents were an asset in the setting of venipuncture and other simple procedures⁹⁰⁻⁹² 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 shown 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.⁹²

The role of FMP for resuscitations, particularly trauma resuscitations, is more controversial.⁹³ Although some parents would not choose to be present during resuscitation, nearly all parents report that they would want the option to choose to be

present or not.^{29,94,95} However, surveys of pediatricians, ED staff, and trauma care providers have noted a reluctance to allow family members to be present during resuscitation.^{30,95-99} Providers often cite fears that it will be traumatic for family members, that families will be disruptive, or that it may result in increased litigation. Trainees seem to be particularly reluctant to endorse FMP.¹⁰⁰

Contrary to ED staff fears, EDs reporting their experience with FMP for resuscitation have noted rare instances of disruption by family members and increased acceptance by staff members once they had experience with FMP.^{30,95,99,101,102} 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.^{29-32,100,102} In addition, ED staff members who experienced FMP report that present family members' appreciation that "everything possible was done" was a benefit to staff members.¹⁰²

Family members who were present for resuscitation of their child report that they felt they served major roles: provided support to decrease their child's anxiety, served as an advocate for their child, and provided timely information for staff. (O'Connell et al; unpublished abstract, May 2012) One study reported a positive effect of FMP on the grieving process when a resuscitation attempt resulted in death.¹⁰³ Others reported no difference in anxiety and family-member well-being in family members who were present versus those who were not during a trauma resuscitation.¹⁰⁴ Structured programs of FMP during pediatric trauma team activations showed no instances of family interference with medical care or procedures.^{72,105} Present family members also report that they are aware of the need to physically and

emotionally regulate themselves during the resuscitation of their child. (O'Connell et al, unpublished abstract, May 2012) Three studies evaluated the time taken for completion of key components of the trauma evaluation and determined that it was not different for trauma team activations with the family present versus those without family presence, and there was no effect on the efficiency of the trauma resuscitation (O'Connell et al, Unpublished Data, May 2012).^{105,106}

Family presence may also improve perceptions of medical decision-making, patient care, and communication among health care providers as well as with family members (O'Connell et al, Unpublished Data, May 2012).¹⁰⁵ Although no studies have directly addressed the effect of FMP on malpractice litigation, there is reason to believe that the presence of family may actually decrease litigation by improving patient and family satisfaction.¹⁰⁷

Although there have been few rigorous studies to date, and patient numbers in most of those studies have been small, there is more clinical evidence to support the benefits of FMP to patient, family, and health care professionals than there is for the competing concerns that FMP might be disruptive during procedures or traumatic to bereaved family members.^{72,108} The Emergency Nurses Association, the American Association of Critical-Care Nurses, the National Association of Emergency Medical Technicians, the American College of Emergency Physicians, and the AAP have all issued policy statements in support of offering FMP in emergency care.^{3,21,109,110} Since 2000, the American Heart Association has recommended offering the option of FMP during resuscitation attempts, and the 2010 guidelines recommend using FMP whenever possible.¹¹¹ Guidelines for FMP have also been integrated into *Advanced Pediatric*

*Life Support: The Pediatric Emergency Medicine Resource*¹¹² as well as the Emergency Nurses Association's Trauma Nursing Core Course and Emergency Nursing Pediatric Course.¹¹³ A national consensus panel that convened in 2005 conducted an in-depth literature review of studies examining FMP and recommended that FMP be encouraged for all aspects of ED care.¹¹⁴ The consensus report described criteria for support staff and for possible exclusion from FMP (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 FMP, fewer than 5% of surveyed institutions reported having a written protocol. However, some institutions have published their experiences with developing and implementing a structured FMP protocol. These examples can be used as a roadmap for institutions that would like to develop and implement their own policies and guidelines. Appendix 2 presents an outline for a protocol for FMP in the ED.

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, the ED provider must weigh the child's ability to understand information about the proposed treatment and its risks and benefits with the parent or guardian's legal decision-making responsibility. 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

to the ED by a parent with the request for drug screening may well be capable of understanding the decision to refuse such testing.¹⁶ The AAP opposes involuntary drug testing on adolescents who possess decision-making capacity unless there are “strong medical indications or legal requirements to do so.”²² ED providers are encouraged to respect an adolescent’s opinion, particularly when the “proposed intervention is not essential to his or her welfare, and can be deferred without substantial risk.”¹⁶ In situations in which the proposed intervention is not necessary emergently and the patient has a reasonable understanding of the medical issues at hand, his or her disagreement should be taken seriously.^{16,23} When this happens, it is reasonable to attempt to explore the issues with the patient and legal guardian in hopes of negotiating a solution that is agreeable to all parties.¹⁶ Decision-making that is family-centered provides an opportunity for a collaborative approach to communication between ED providers, patients, and their families.² There is, however, a delicate balance between the ethical and legal issues regarding consent. 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. That child’s refusal merits serious consideration by ED staff, although he or she most likely would not be granted mature minor status in court. Consultation not only with parents and the child’s subspecialty care team but also potentially with the primary care physician, palliative care team, chaplaincy, or hospital ethics team may be helpful. A patient’s ability to participate in decision-making varies depending on developmental stage and the ability to understand the issues involved, with the child providing assent whenever reasonable.¹¹⁶ The legal aspects of when and under what circumstances minors can refuse and consent to medical treatment are

complex^{115,116} and vary by state. ED health care professionals may not be able to resolve them in any particular case without the assistance of resources outside the ED.

When the Family Refuses a Proposed Treatment

It is not uncommon in the acute care setting for the 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 procedure, 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 for their child. If those choices place their child at risk of serious complications, ED providers are obligated to follow institutional policies and state law for reporting issues of child abuse or neglect.¹² Alternatives in care can be discussed with the family, keeping in mind patient safety and the interest of the child.¹² 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 antibiotic agents may exist in some circumstances. 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 advantage of a procedure (such as obtaining a sterilized cerebrospinal fluid sample) or the potential risks associated (such as 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. 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 provider and may weigh medical evidence very differently.”¹⁴ 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. Provider liability in these circumstances is best addressed by careful 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 constitutes medical neglect, the appropriate child protective services agency should be contacted.⁷⁹

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. Involvement of the family, with clear communication and a willingness to negotiate an alternative that is acceptable to all,² while at the same time documenting the discussions and reasoning used to arrive at the negotiated agreement, is a PFCC practice. States vary regarding who has the temporary authority to hold a pediatric patient in the ED against the parents' wishes. ED providers should be aware of their state-specific laws and institutional practices regarding families who leave against medical advice. If a family leaves before or without such a discussion (a category often labeled "left without being seen" or "left without completing treatment"), it is a good practice to attempt to contact the family to inform them of the potential for adverse outcome to the child and a willingness to have the patient return to the ED or to assist with follow-up in the medical home.

All states have a process to respond to varying levels of urgency when there is refusal of care. The time frame of an ED visit often requires a timely decision, 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."¹¹⁷ The urgency of some situations requires proactive ED planning and a well-defined process for resolving a refusal of care, including, if needed, emergency custody.

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.¹¹⁸ However, it is important to remember that the intent of such reporting is to protect the child, a goal that most families will acknowledge, even those in whose care abuse or neglect is suspected to have occurred.¹¹⁸ 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 can facilitate family cooperation with other professionals during an investigation.¹¹⁸ Family involvement in a child's care continues in the ED even if maltreatment is suspected,⁴⁴ with respectful and compassionate support offered similar to that given to all families.¹¹⁹ ED policies for suspected cases of child abuse or neglect can provide for family supervision⁴⁴ while ED providers work with child protective services to ensure an appropriate safety plan during the child abuse investigation.

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,^{5,6,120-122} and family input may be beneficial. Having protocols and procedures in place is critical for anticipating the needs of family members, who often arrive separately from their child, with significant emotional distress. Under such circumstances, immediate response from designated, trained staff members 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,¹²² the medical examiner, child protective services, and organ- and tissue-procurement teams.⁶ Protocols should address a plan for safe and compassionate FMP and identify additional resources available to the ED, such as social services, chaplaincy, acute psychiatric services, and child life services. Space should be designated for family privacy, with adequate seating, local and long-distance telephone capability, and an accessible restroom, tissues, water, and writing materials. Written materials can reinforce and provide additional advice on how to support grieving children both immediately and over time.¹²³

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 guidelines^{5,120,124} 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 organ/tissue donation; contacting important family supports, such as members of the family's faith community and medical home; 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. State requirements for medical examiner jurisdiction vary, which can affect an ED's ability to allow family private or accompanied time with the body. 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 process of bereavement for parents and siblings, and ED health care professionals can have a profound effect.^{5,6,121}

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

Practice Statement

FMP 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, social worker, child life specialist, paramedic, or other suitable staff member) assigned to support the psychosocial needs of the family; this person should not be needed for the immediate resuscitation or direct assistance with the invasive procedure

Procedure (Utilizing Interpretation When Needed)

- Designate a 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 and needs and how to address them with accessible and appropriate ED resources.
 - Exclusion criteria may include combativeness, agitation, extreme emotional instability, altered mental status, intoxication, or patient preference. Families who do not wish to participate should be supported in that decision and should be supported by the family support facilitator or other ED staff while they are separated from the patient. If the family is not offered the option of FMP, 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).
 - Inform the patient and family of next steps and what they can expect (eg, facilitator will consult with the ED health care team and determine when the family will be escorted to the patient's bedside, etc).
- Consult with health care team: As early as possible, the family support facilitator will inform the health care team of the family's presence. Discuss with the team the family's wish to be with the patient, as well as any patient preferences. 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) and patient: 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 and safety 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 and patient agree to the structure of their time at the bedside and understand any follow-up procedures and their primary contact on the health care team.

- 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 regardless of time spent at the patient's bedside to ensure the family understands what happened and any follow-up care necessary.

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: <http://www.emscnrc.org>
- EMSC Toolbox on Patient and Family-Centered Care: http://www.emscnrc.org/EMSC_Resources/Family_Centered_Care_Toolbox.aspx

Emergency Nurses Association

- *Emergency Nursing Clinical Practice Guideline: Family Presence During Invasive Procedures and Resuscitation*. Des Plaines, IL: Emergency Nurses Association; 2012. Available at: <http://www.ena.org/practice-research/research/CPG/Documents/FamilyPresenceCPG.pdf>
- *ENA Position Statement: Family Presence at the Bedside During Invasive Procedures and Resuscitations*. Des Plaines, IL: Emergency Nurses Association; 2010. Available at: <http://www.ena.org/SiteCollectionDocuments/Position%20Statements/Archived/FamilyPresence.pdf>

Institute for Patient- and Family-Centered Care WebSite Links

Free downloads: www.ipfcc.org/tools/downloads.html

Assessment tools: www.ipfcc.org/resources/other/index.html (cost)

Guidance publications: www.ipfcc.org/resources/pinwheels/index.html (cost)

Health Resources and Services Administration

Culture, Language and Health Literacy. Available at: www.hrsa.gov/culturalcompetence/index.html

National Quality Forum (NQF)

A Comprehensive Framework and Preferred Practices for Measuring and Reporting Cultural Competency: A Consensus Report. Washington, DC: National Quality Forum; 2009. Available at: www.qualityforum.org

Society of Pediatric Nurses

- Lewandowski LA, Tesler MD, eds. *Family-Centered Care: Putting It Into Action: The SPN/ANA Guide to Family-Centered Care*. Oak Creek, WI: Society of Pediatric Nurses; 2008
- Society of Pediatric Nurses. Position statement: safe staffing for pediatric patients. Available at: <http://www.pedsnurses.org/cm/ld/fid=57&tid=28&sid=51>

AAP, Section on Home Care Parent Advisory Group

Available at: www2.aap.org/sections/homecare/pag.cfm

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