PEDIATRICS

Patient and family–centred care for pediatric patients in the emergency department

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ABSTRACT

Patient and family–centred care (PFCC) is an approach to health care that recognizes the integral role of the family and encourages mutually beneficial collaboration between the patient, family and health care professionals. Specific to the pediatric population, the literature indicates that the majority of families wish to be present for all aspects of their child's care and be involved in medical decision-making. Families who are provided with PFCC are more satisfied with their care. Integration of these processes is an essential component of quality care. This article reviews the principles of PFCC and their applicability to the pediatric patient in the emergency department; and it discusses a model for integrating PFCC that is modifiable based on existing resources.

Key words: family-centred care, family presence, pediatrics, emergency medicine, emergency department, patient-centred care

RÉSUMÉ

Les soins axés sur le patient et la famille (SAPF) constituent une autre façon d'envisager les soins de santé. Ils reconnaissent le rôle intégral de la famille dans les soins de santé et favorisent la collaboration mutuellement bénéfique entre le patient, la famille et les professionnels des soins de santé. En ce qui a trait aux enfants, la littérature indique que la majeure partie des familles désirent être présentes pour tous les soins prodigués à leur enfant et souhaitent prendre part aux décisions médicales. De plus, les familles qui reçoivent des SAPF sont davantage satisfaites de la qualité des soins. L'intégration de ces pratiques est un élément essentiel de la prestation de soins de qualité. Cet article passe en revue les principes des SAPF et leur applicabilité aux enfants dans un service d'urgence. Il présente également un modèle d'intégration des SAPF modifiable en fonction des ressources existantes.

Introduction

Patient and family–centred care (PFCC) is an approach that recognizes family members as the constant in a patient's life and, specific to the pediatric setting, acknowledges the strengths they bring to their child's health care

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experiences. Although PFCC has historically been applied to patients who have chronic illness, often in a hospital environment, it is applicable to patients of all ages in all health care settings.[1]

PFCC has been reported to be best practice in health care settings.[1] Its principles are consistent regardless of where the modality is applied (Box 1), and it recognizes the family as central to the child's life. PFCC accepts parental expertise as an information resource for a child and an important component of health care delivery.[1] Research has demonstrated that family members are usually the most knowledgeable about a patient's goals, preferences and values. Family members predict patient wishes better than health care providers, and adults prefer that their families, rather than strangers, make decisions for them.[2]

PFCC acknowledges the uniqueness and diversity of children and families by supporting the family's coping methods, and emphasizing collaboration.[1] An important aspect of PFCC in an emergency department (ED) setting is that it gives family members the option to be present during medical interventions, including resuscitation, procedures and transport.

Involving families and pediatric patients in medical decisions

Communication is essential to the application of PFCC.[3] Most patients, even if acutely ill or injured, want to be involved in decisions regarding their care. Parents of pediatric patients prefer shared decision-making and report dissatisfaction when this does not occur.[3,4] Moreover, health policy and ethical considerations affirm the right of patients to have a role in medical decision-making.

Research supports the importance of PFCC, especially regarding the development of collaborative relationships between families and health care providers.[5] The value that parents place on the health care providers who care about them is emphasized though PFCC, which allows a collaborative relationship based on the negotiation of each individuals' respective role, trust and open communication.[5]

Box 1. Principles of patient and family–centred care

1. Treat patients and families with dignity and respect.
2. Communicate unbiased information.
3. Patient and family participate in experiences that enhance control and independence and build on family strengths.
4. Collaborate in the delivery of care, policy and program development, and professional education.

Traditionally, parents and physicians have made medical decisions on behalf of children. The need for collaboration with pediatric patients, especially adolescents, is a valuable aspect of medical decision-making. As the American Academy of Pediatrics stated, "in some circumstances, children deserve to make their own decisions based on a child's capacity for participating in the decision-making process."[6] Family and health care practitioners should collaborate to determine the child's role in medical decision-making. PFCC respects the parent–child relationship, and the child's dependence, vulnerability and decision-making capacity. Actively involving a child in his or her own health care can improve parent and child satisfaction, increase the child's knowledge of the prescribed therapy and improve the child's overall functional status. Increased patient satisfaction improves compliance with discharge instructions, thereby potentially improving outcomes.[7]

Developmental issues must be considered when communicating medical information and weighing patient input on medical decisions. Infants and preschool children have no significant decision-making capacity and cannot provide consent to care or refuse care in an informed manner. Primary school-aged children may indicate their assent or dissent but may not fully understand the implications of their decision. They should be provided with information appropriate to their comprehension level. Although many adolescents have the decision-making capacity of an adult, this capacity must be determined on an individual basis. The age of 18 years, while a convenient legal threshold, has no scientific validity as the point at which individuals become competent decision makers.[8] Research indicates that 14- to 17-year-olds are competent to provide consent to abortion.[9] Factors to consider when communicating information and weighing decision-making capability include the child's ability to choose independently, to assess risks and benefits, and to consider multiple options. Achievement of a stable set of values is important. Many adolescents need assistance in understanding issues at a level sufficient for informed decision-making. The disclosure of patient information, which is often necessary to provide patient care and PFCC, should be in accordance with applicable laws and regulations.

Family member presence for procedures and resuscitation

Family member presence (FMP) is one aspect of PFCC. FMP is defined as the presence of family in the patient care area, in a location that affords visual and/or physical contact with the patient during invasive procedures or

resuscitation events. FMP during procedures and resuscitation is an important yet controversial issue.

The American Heart Association emergency cardiac care guidelines recommend family members be given the option to be with their loved ones during resuscitation efforts.[10] Pediatric advanced life support (PALS) guidelines endorse FMP during the resuscitation of children,[10] but many health care providers are uncomfortable with this. The conference on Family Presence During Pediatric Cardiopulmonary Resuscitation and Procedures, consisting of 18 organizations, developed consensus recommendations advising that FMP is an option during procedures and resuscitation after consideration of health care team safety and the assessment of factors that could adversely affect the interaction. These recommendations advise that if FMP is not an option, then the reasons why should be documented, a legal review of FMP policies should be obtained, education in FMP should be provided and FMP research should be promoted.[11]

Studies indicate that only 17% of surgeons and 36% of emergency physicians are supportive of FMP[12]; nurses appear more supportive of this practice.[12,13] A survey of pediatricians found that 65% would not allow FMP during a resuscitation.[14] Inpatient specialists and residents are more likely to allow FMP than outpatient specialists.[14] Another study found that critical care staff are more comfortable with FMP.[15]

Emergency physicians believe that the physician alone (44%), or the physician and parent (21%), or the parent alone (19.1%), or the parent, the nurse and the physician (11.4%) should decide on FMP. The nurses believed the decision should be made by the physician alone (10%), by the parent and physician (4.3%), by the parent alone (24.3%), or by the parent, nurse and physician (10%).[13] In another study, investigators found that FMP during resuscitation was supported by 92% of nurses, 78% of attending physicians and 35% of residents, and that training level affected physician comfort with FMP.[16]

Staff concerns about FMP

Staff concerns about FMP included the following:

- The encounter would be a traumatic, haunting experience for the family.
- Families would be disruptive.
- The experience would be too emotional for the staff.
- Families would be offended by comments.
- Increased staffing requirements would be necessary.[16]

Studies indicate that FMP does not affect provider anxiety or performance.[17] In institutions where FMP exists, the majority of staff members were reported to be supportive and without increased anxiety.[15,18] A study of 5 EDs found previous experience with FMP was the most important determinant of a favourable opinion regarding this issue.[18] Education about FMP can alter emergency department (ED) staff attitudes.[19] Hospitals with FMP policies have reported no difference in staff actions or episodes of disruption. Moreover, staff felt that families' behaviour was appropriate and that FMP should be continued.[20] One pediatric ED found that FMP led to uninterrupted patient care, with no negative impact.[19] FMP has also been shown to provide cost savings for hospitals through being more comfortable with the withdrawal of care thereby reducing intensive care unit costs.[21]

One fear expressed by staff is "getting sued."[13] We found no published reports of malpractice claims resulting from PFCC or FMP. Moreover, 1 report suggests that these processes may reduce malpractice risk,[22] likely because satisfied patients are less likely to file malpractice claims.[22] There is a strong positive relationship between patient satisfaction and provider–patient communication, and efforts that enhance the patients' understanding of their care and processes of care.[7] FMP is 1 component of PFCC. Both FMP and PFCC promote communication but PFCC is the larger encompassing umbrella that includes FMP.

Do families want to be present for procedures or resuscitation involving their children?

When parents in an ED waiting room were queried, 94% wanted to be involved in the decision about whether or not to be present with their child; and the majority stated a desire to be present for venipunctures, intravenous (IV) catheter placement, lumbar punctures and endotracheal intubation.[23] Surveys of the families of patients who have died in the ED indicate that most families would have liked to be present or be given the option of being present during resuscitation efforts.[24] For adult patients, families felt their presence might have benefited the patient and their own grieving.[24] Families of pediatric patients also felt that it would help their child and ease their fears.[15]

What is the effect of FMP on families?

Randomized controlled trials of ED patients undergoing venipuncture, IV placement or urethral catheterization found FMP reduced both patient distress and parent anxiety.[25,26] A study in a pediatric intensive care unit found that parental presence reduced patient anxiety and parents felt their presence was helpful to themselves and to their children.[27] A randomized controlled trial of FMP for lumbar puncture found no difference between groups in anxiety testing, and all participants reported that they would

choose to be present in the future.[28] After FMP for resuscitation was initiated in 1 hospital, a survey indicated that all present family members believed "everything was done"; 94% would choose to be present again, 76% believed being present "helped" their grieving and 64% felt that it was helpful to the patient.[23] A randomized controlled trial found less depression, anxiety and grief in family members who had been present for a resuscitation. No family members left the resuscitation room or regretted that they had been present, and 88% believed that their presence helped the bereavement process.[27] In families of pediatric patients who were surveyed 3 months after their presence at a resuscitation or during invasive procedures, no parents had traumatic memories.[15]

Implementing PFCC

The Emergency Nurses Association (ENA) published a statement supporting FMP and a "how to booklet" for initiating PFCC or FMP in the ED[29,30] (Box 2). The National Association for Emergency Medicine Technicians (NAEMT) website has guidelines for providing PFCC.[31]

Although hospitals may lack resources for a comprehensive program, simple modifications can facilitate the implementation of PFCC. The approach to integrate PFCC can be applied in any size hospital and involves

1. determining need;
2. evaluating policies and procedures for PFCC principles;
3. establishing a unified departmental and hospital philosophy;
4. educating staff;
5. instituting and modifying policies and procedures; and
6. assessing the current environment and making modifications (Box 3).

Box 2. Steps to implement a patient and family–centred care (PFCC) approach

1. Evaluate families' needs. Surveys, conversations with families, focus groups and family advisory committees are strategies to gather information.
2. Develop a mission, vision and philosophy of care that includes PFCC.
3. Evaluate policies and procedures for congruency with PFCC.
4. Educate staff on family needs, communication and the family perspective. Engage family members to assist with staff education from the family perspective.
5. Develop staff competencies related to PFCC.
6. Provide an environment that is child and family friendly, including furnishings, fixtures, availability of toys and play activities.

A child-friendly environment is a component of PFCC and can reduce the pain and distress of an ED visit. Recommendations for creating such an environment include the use of private rooms, toys or games for diversion, and a calming environment that includes colourful walls and pictures on the ceiling.[19] In addition, child life specialists (i.e., individuals trained to assist with the child, sibling and family, as well as provide resources and support for the family) can be beneficial.

PFCC in special circumstances

Children with special health care needs and chronic medical problems

PFCC is at least partially attributable to an advocacy movement by people with disabilities and parents of children with special health care needs. Parents of children with disabilities, chronic illnesses or both reported less stress and better emotional well-being when the care they received was more family-centred.[32] Involving parents in care and allowing them to facilitate interventions has been shown to reduce children's pain, anxiety and distress.[33] Failure to enlist family participation and support in these children may lead to errors, both of omission and commission.[34] It is important to involve the family when decisions are made regarding the extent, duration and type of therapy that will be provided to a child with special health care needs or to a child with chronic medical problems.[35]

Trainees and PFCC

The American Academy of Pediatrics Task Force on the Family was designed to assist public policy development and guide pediatricians to promote well-functioning families. This group concluded that children's outcomes are strongly influenced by how well their families function,

Box 3. Potential problems or constraints that should be addressed in a family member presence (FMP) policy

1. Ability to allow for FMP if no family support person is available.
2. How to manage situations in which family members exhibit behaviours that may obstruct care.
3. How to manage situations in which families express their opinions about the need to continue or cease resuscitation efforts.
4. Limitations on space in the resuscitation or procedure room.
5. Need for an interpreter to communicate with the family.

and there is much that pediatricians can do to help nurture and support patients' families. The task force further suggested family content should be included in residency training and continuing medical education of practising physicians. Studies indicate that staff with the least experience are most likely to be opposed to FMP.[18,28] Residents differ considerably from attending physicians in their comfort with this process.[36] In a survey of 51 residents, they reported that they cared for relatively few end-of-life patients during their training (a median of 10 inpatients).[37] Only 16% reported good or outstanding palliative care training.[37] A death and bereavement seminar for pediatric residents emphasizing family support strategies and parental perceptions of medical care providers and their dying child was deemed valuable by residents.[38] Residents generally accepted the presence of family members for procedures, but were less comfortable with this during CPR.[36] A trend toward greater comfort and acceptance of FMP was found as training levels increased. Approximately 45% of residents reported that their major reservation about this concept was that their anxiety could result in procedure or resuscitation failure.[36]

There are available curricula that support PFCC and include FMP, cultural competency, chronic care pediatrics and patients with handicapping conditions. The ability to observe faculty as role models and the provision of feedback regarding interactions with families may solidify PFCC as part of the practice of medicine.

Child maltreatment

Sensitivity is required if separation of a child from his or her home is being considered because of suspected or confirmed maltreatment. While the child is undergoing care, the family should be involved in that care, even if maltreatment is considered a possibility.[39] Barton reported that providing support and resources to mothers, even when the mothers are abusive, may result in a reduction of violence and abuse for the mothers and their children.[39] Any assumption of guilt or innocence should be unrelated to the decision to include the family in medical decision-making and psychosocial support. Appropriate family supervision should be maintained throughout the child's stay. Guidelines exist for PFCC when maltreatment is suspected.[39] Resources are also available for high-risk families that are not currently abusive but have the potential to escalate. Early use of family-centred resources may prevent maltreatment in such situations by stabilizing the family.[39]

Adverse events

When adverse events occur during patient care, fear of litigation may motivate physicians to abandon PFCC and retreat into "defensive medicine." While communicating with a family about an adverse event is challenging, doing so may actually lower the risk of litigation. Many patients and their families embark on legal action because they suspect a cover-up or because they want more information.[22] It is ironic that physicians may fail to disclose error based on fear of malpractice, when nondisclosure itself may lead to further legal action.[22] When families are confronted by silence or evasion, they may see litigation as the only tool to rectify the imbalance of power and knowledge.[22] One study found a hospital's malpractice claims declined after instituting a policy of active disclosure of adverse events to patients.[40]

Conclusion

PFCC is a process that is applicable to patients of all ages in any setting, and it is integral to providing quality care. It acknowledges the essential role of the patient and family as well as the importance of a partnership between the patient, family and health care providers. PFCC allows patients and families to be involved in medical decision making, and it allows family member presence during procedures and resuscitations, when appropriate. Components for implementing this process include

- developing a philosophy of PFCC along with policies and procedures that incorporate patient and family input;
- educating staff; and
- providing a friendly environment for the patient and his or her family.

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