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Family Presence in Emergency Medical Services for Children

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The presence of family at the bedside during a cardiopulmonary resuscitation is uncommon in most institutions and has generated strong debates within the healthcare community during the past decade. However, the time-honored practice of banning families from the bedside during emergency procedures appears to be grounded by tradition rather than by evidence based on the outcomes of actual family presence (FP) events. Family presence is explored within the framework of patient-family–centered care and from the context of resuscitation outcomes. The focus of this review examines research findings investigating the effects of FP during cardiopulmonary resuscitation and invasive procedures on family members, patients, and providers. The process of developing FP programs based on models of evidence-based practice to promote quality patient care is described. Finally, the application of FP to the prehospital environment is explored.
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Family presence (FP) involves the attendance of the family member(s) in a location that affords visual or physical contact with the patient during a cardiopulmonary resuscitation (CPR) or invasive procedures (IPs) [1]. However, bringing families to the bedside of a loved one during an emergency procedure is uncommon in most institutions. Recently, this topic has generated strong discussions both for and against the practice. Among the multiple arguments against FP, perhaps the one most compelling and frequently cited, based on hypothetical survey data, is that the event might be so traumatic for families that they could lose emotional control and, as a result, interrupt patient care and the operations of the medical team [2-9]. Also, based on hypothetical survey data, others have reported that providers fear that FP could intensify the risk of litigation [2,3,5-8], make healthcare providers unsettled, causing their technical skills to decline [2,3,5,6,9], and infringe the patient's confidentiality and privacy rights [7,10]. However, no evidence exists to support any of these arguments. Thus, the time-honored practice of banning families from the bedside during emergency procedures appears to be grounded by tradition rather than by evidence based on the beneficial or adverse outcomes of actual FP events.

Providers from Foote Hospital, Jackson, MI, in 1985, were the first to question the long-established practice of

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excluding families from the bedside when they conducted a survey of 18 family members who had recently lost a family member undergoing CPR [11]. When they discovered that 72% of these families would have wanted to be present during their loved one's resuscitation [11], they developed and evaluated a program that offered family members the option of bedside presence. Of the 70 family members who were involved in actual FP events of 30 patients (all died) during CPR, 47 (67% family response rate) returned surveys. Most believed that everything had been done for their loved one, that their presence was beneficial for their dying family member, and that their grieving was facilitated because they were there. Moreover, the researchers documented that families had not been disruptive, made no attempts to impede the operations of the medical team, and did not interfere with patient care. Although this study was small and the first of its kind, evidence documenting the beneficial effects for family members and absence of negative outcomes challenged traditional thinking about banning all families from the bedside and suggested that provider fears about FP may be unwarranted. As a result of this seminal study, the pioneers at Foote Hospital also opened the door for debate about FP in the nursing, medical, and lay communities and laid the foundation for future research.

Cardiopulmonary Resuscitation Outcomes as Context for Family Presence

Despite our very best efforts, most resuscitation events result in death [12]. These CPR outcomes are part of the context in which FP must be evaluated [13]. Statistics show survival rates after cardiopulmonary arrests ranging from 1% to 20% for out-of-hospital arrests [14]. Survival after an in-hospital arrest is reported to be less than 17% [15], though the dissemination and deployment of automated external defibrillators is expected to shorten the time to defibrillation and remains a fundamental goal of the healthcare system [16].

Though cardiac arrest from a cardiac cause is uncommon in the pediatric population, it can follow a terminal event of respiratory failure or shock [12]. Statistics reveal that ventricular fibrillation (VF) occurs in 5% to 15% of all pediatric victims of out-of-hospital cardiac arrests, and it is reported to occur at some point during a resuscitation event in up to 20% of pediatric in-hospital arrests. The incidence of VF increases with the age of the child. Defibrillation, the definitive treatment of VF, is associated with an overall survival rate of 17% to 20% [12]. Defibrillator use for shockable rhythms has been recommended for children with appropriate energy adjustment. Automated external defibrillators can be safely and effectively used in children aged 1 to 8 years [12]. Nonshockable rhythms such as asystole and pulseless electrical activity are treated with CPR and pharmacotherapy [12].

Some healthcare providers have been reluctant to involve family members in viewing or participating in CPR [13,17]. Initially, CPR was strictly performed only by physicians in the 1960s. Shortly after Kouwenhoven et al [18] published their landmark article about cardiac massage, nonphysicians, including fire fighters, nurses, and the general public, were intrigued with the apparent simple technique that could potentially reverse sudden death [18]. It was only after physicians were comfortable with this technique that controlled teaching of lay people occurred, spurring quite a debate in the medical world [18]. Nonhealthcare providers were slow to be incorporated into the culture of resuscitation events.

Fortunately, current evidence about cardiopulmonary arrest suggests an even greater recognition of the role for laypersons in the field. Two recent studies demonstrated improved patient outcomes based on the timely interventions of volunteer citizens who performed CPR when they witnessed an arrest [19,20].

Studies and Evidence About Family Presence

Most of the literature to date describes FP during CPR events and/or during IPs. An analysis reveals that at least 3 different types of articles have been published—articles focused on provider beliefs, concerns, and fears about the possibility of FP; surveys centered on hypothetical "what if we tried it" scenarios; and evidence drawn from actual studies of people who participated in FP during a resuscitation event. In the third category of actual participants, all of the studies took place in hospital settings; however, descriptions of FP during the transition between prehospital settings and hospital environments have been reported. Accounts of family members who initiated CPR while awaiting the arrival of emergency medical services (EMS) serve as reminders of the logical and natural extension of FP during resuscitation as the efforts continue. Meyers et al [21] reported that family members were already with the patient in one third of the cases of FP at the onset of resuscitation in out-of-hospital settings and assisted in summoning help and giving aid. Berger and other physician colleagues [22] note that the interval between the intervention of CPR and knowing the outcome is brief, usually in minutes. They suggest that the benefit to families stems from the opportunity to share a loved one's last minutes of life.

What do Family Members Say?

Burgeoning consumerism may be the major driving force behind the FP during resuscitation movement, as patients

and family members are becoming savvy consumers of healthcare [23]. According to the new American Heart Association CPR Guidelines [12], most family members would like to be present during resuscitation events. Polls of public opinion by national news organizations, such as NBC Dateline [24] and USA Today [25], show that most of the public (about 70%) favors staying with their loved one. Cumulative results from national and local surveys reveal that between 60% and 80% of families believe that they want to be present in the emergency department with a loved one who is undergoing emergency procedures [24-30].

A surprising number of studies involving actual FP events have found that the most family members accept the option to be present during CPR and IPs. Some of the reported benefits to family members who participated in FP events include (1) continued patient-family bonding and connectedness [21,31]; (2) facilitation of the grief process [11,17,32-38]; (3) sense of closure on a life shared together [21,32]; (4) removal of doubt about what was happening to the patient and the knowledge that everything possible was being done [11,17,21,31,32,34,36,39]; (5) a spiritual experience [21]; (6) feeling that they had been supportive and helpful to the patient [11,21,31-33,37,38,40-42]; and (7) reduced fear and anxiety [36-38,42,43].

Concerns about possible disruptions in medical care as well as potential emotional trauma to family members have been raised and studied. No disruptions in care provided during FP events have been reported by investigators [8,11,21,30,32-34,36,44]. In fact, one randomized control trial of FP was stopped early because the staff was convinced of the benefits to families [36]. An analysis of 193 videotaped recordings of family members and their emotional responses during resuscitations at 3 level 1 trauma centers in the United States has been described [45], and no family members lost control or interfered with medical care. Studies of family members, including those spanning several weeks after the event (consistent with crisis theory), found no adverse psychologic effects [8,21,36]. In addition, research findings reveal that given a similar opportunity to participate in FP, nearly all family members would do it again [8,11,21,38]. Poignant family member responses of gratitude for being able to experience FP during resuscitation are reported [13].

What do Healthcare Providers Say?

A significant number of national professional organizations have published guidelines and endorsements for healthcare providers recommending FP during resuscitation. One of the most important international groups, the American Heart Association, initially incorporated recommendations in the *Guidelines 2000 for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care* [46] and, more recently, in the updated *Guidelines 2005* [12]. This group, composed primarily of physicians, specifically suggests that "healthcare providers should offer the opportunity [for FP during resuscitation] when possible" [12]. Several other professional organizations are now recommending this practice through educational programming, including Emergency Medical Services for Children (EMSC) [47]; the Pediatric Advanced Life Support course [48]; *Advanced Pediatric Life Support (APLS): The Pediatric Emergency Medicine Resource* [49] developed jointly by the American Academy of Pediatrics, Elk Grove Village, IL, and the American College of Emergency Physicians, Dallas, TX; the Emergency Nursing Pediatric Course [50]; and the Trauma Nursing Core Course [51]. In addition to an endorsement by the Canadian Association of Critical Care Nurses, London, Ontario [52], another major endorsement has been issued by the American Association of Critical-Care Nurses, Aliso Viejo, CA, whose recently published *A Practice Alert on Family Presence* recommends that all patient care units develop a written document for FP and that family members of all patients be given the option of being present at the bedside [53]. The Emergency Nurses Association (ENA), Des Plaines, IL, was the first major national nursing organization to recommend FP during resuscitation [1,54,55].

When the need to comply with national guidelines is incorporated into the dialogue about FP, the arguments for implementing FP into routine practice may become even more powerful. Nevertheless, some providers are just hearing about this phenomenon for the first time and may naturally have concerns about implementation, including possible emotional stress and even trauma to family members. An interesting finding in several studies shows that healthcare providers who initially opposed FP often become the most fierce advocates for it after witnessing its many benefits for families and patients [21,36,56].

Over a decade of research can be found describing trends about health care providers and FP [13,23,57,58]. Trends that have been reported include the following: (1) nurses are more supportive of FP than physicians [5,7,21]; (2) experienced physicians favor FP more than those who are in training [2,21]; (3) nurses who were certified in emergency nursing, holding bachelors or masters degrees, and working in emergency departments have more positive attitudes about FP than nurses in other hospital areas [59]; (4) more female healthcare providers support FP than do male healthcare providers [21]; (5) use of a designated family facilitator whose attention is on the family member permits the team to continue care focused on the patient and is recommended by the ENA [1], the American Heart Association, Dallas, TX [12,48], and others [13,21,50-53]; and (6) education about FP during resuscitation improves attitudes and acceptance [60]. The influence of non-US cultures has not been well

Table 1

EMERGENCY CENTER POLICY AND PROCEDURE

Presenting the option of family presence during IPs and/or resuscitation interventions.*

I. Purpose

To offer family members the *option*, when appropriate, of being at the bedside during invasive procedures (IP) and/or resuscitation interventions (RI). Family Presence: The attendance of the family members in a location that affords visual or physical contact with the patient during IP or RI.

II. Policy

The option of family presence at the bedside during IP and/or RI will be offered to the family, providing that the following criteria are met:

A. Uninterrupted patient care will remain the priority.

B. A member of the Health Care team (family facilitator) will assess the patient family for appropriateness of family presence.

1. Members of the Health Care team shall participate with the family facilitator in evaluating whether families are suitable candidates for bedside presence.
2. Before the family presence option is offered, families will be assessed for appropriate levels of coping and the absence of combative behavior, extreme emotional instability, and behaviors consistent with altered mental status.
3. Suspected child abuse is an absolute contraindication to family presence.

C. The physician in charge/direct care provider is informed of and is in agreement with the option of family presence.

D. The family will be offered the option of family presence. Family members who do not wish to participate will be supported in their decision.

E. A maximum of two family members may be present at the bedside at a given time. When prioritizing family member visitation and determining next of kin, the members of the Health Care team will use Administrative Policy *Disclosure and Informed Consent* 2.04.

F. Before entering the room, the family facilitator will prepare the family for bedside presence. He/she will explain that patient care is the priority.

He/she will describe the patient's appearance and condition, procedures being performed, and the importance of the family's supportive role.

G. The family facilitator will provide the family with personal protective equipment as appropriate. The health care team will instruct the family members where to stand and what they may or may not touch to prevent contaminating the patient or supplies during a sterile procedure.

H. The family facilitator will escort the family to the bedside and remain with the family during the bedside presence until, upon collaboration with the health care team, it is appropriate for the facilitator to depart.

Table 1 (*continued*)

EMERGENCY CENTER POLICY AND PROCEDURE

Presenting the option of family presence during IPs and/or resuscitation interventions.*

I. When in the room, the family facilitator will:

1. Provide comfort measures, such as a chair at the bedside or tissues.
2. Provide opportunities for families to ask questions.
3. Facilitate opportunities for the family to see, touch, and speak to the patient.

J. If a family member becomes faint, overwhelmed, or disruptive at the bedside, the family facilitator will immediately escort him or her from the area and arrange appropriate supportive care.

K. After completing the patient bedside visitation, the family facilitator will escort the family to a comfortable area, address their concerns, provide comfort measures, and address other psychosocial needs identified during the intervention.

L. If members of the Health Care team involved in a family presence identify the need for debriefing regarding the case, the area supervisor will facilitate an immediate and appropriate processing and debriefing of the incident.

M. The family facilitator will communicate the need for family follow up to the appropriate social worker.

III. Guidelines

A. Will patient care be interrupted if family members are present?

B. Has the family been screened for appropriateness of bedside presence?

C. Is the physician in charge/direct care provider in agreement with family presence?

D. Is family aware that only two members will be permitted in the patient care area at one time?

E. Is a family facilitator available to remain with the family until it is appropriate for the facilitator to depart?

F. Has the family been prepared for bedside presence?

G. Is the family aware that they can step out of the patient care area at any time?

H. Is the family aware that they may be asked to leave at any time at the discretion of the physician in charge/direct care provider?

I. Has the family been assured that they will be frequently updated if they choose not to be at the bedside?

J. Was family presence documented in the nursing or progress notes?

IV. Responsibility

Physician, Nursing, Respiratory Care Practitioner, Clinical Technician, Social Work, Child Life, Pastoral Care, Translation Services.

V. References

Emergency Nurse Association (ENA) guidelines for Presenting the Option of Family Presence, Park Ridge, IL, ENA, 1995.

Parkland Health and Hospital System, Protocol for Family Presence During IPs and Resuscitation, Dallas, TX, 1999.

Administrative Policy *Disclosure and Informed Consent* 2.04. Children's Medical Center, Dallas, TX, 75235.

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documented. Ong et al [3] found dissimilar support for FP during resuscitation—78% of Asian nurses did not support it, which contrasts with US studies showing that most nurses support it. A British study [61] found 70% physicians and 82% nurses in support.

What do Patients Want?

Because most people who undergo resuscitation do not survive the event, data are limited about their experiences and preferences. In the Parkland Hospital study, 17 of 19 patients with attempted resuscitations died [62]. Researchers reported on data from phone interviews done 2 months after the emergency event of 9 patients who had family members present—8 during IPs and 1 during CPR. Themes derived from the analyses revealed that patients received comfort from family members, felt family acted as their advocates, believed family reminded the medical staff that the patient was a real person, increased connectedness to their family, and perceived that FP was a right. They spoke of the realization that FP was potentially stressful for their family members but that the benefits outweighed the risks. Robinson et al [36] reported data on 3 patients who survived resuscitation and felt supported by their family's presence, without any compromise to their privacy or dignity.

Evidence-based Practice Guidelines for Family Presence—a Model

The process of establishing written FP protocols has been described by the ENA and others [1,63,64]. Guided by models of evidence-based practice (EBP) to promote quality patient care [65], it is recommended that a written FP EBP guideline (ie, a FP policy, procedure, or standard of care) be developed based on the best available evidence and then piloted and evaluated to determine whether the guideline should be adopted in clinical practice.

Assess Institutional Readiness

In developing a FP program with written EBP guidelines, the ENA recommends that project champions be identified who are interested and committed to initiate change [1] and a multidisciplinary project team be assembled who are dedicated to patient-family–centered care and advocates of FP (ie, nurses, physicians, social workers, child life specialists, and chaplains) [64]. The project team begins by assessing the vision statement of the institution and its readiness for FP. Patient-family–centered care, the foundation of holistic practice and the cornerstone of FP, is grounded in an institutional philosophy that supports the integrity and wholeness of the family unit and is driven by the needs of the patient-family [66]. In the case of pediatric emergency events, for example, parents overwhelmingly want to remain with their child [27,33,38]. Likewise, nearly without exception, children desire to have their parents with them during such events [67-69]. Thus, the project team should assess the institution's commitment to patient-family–centered care, its level of support for patient-family–centered care principles, and the degree to which these principles are integrated in management and clinical practice based on current practice [1]. It also is recommended that the team assess the institution's human and fiscal resources needed to support a FP program as well as risk management concerns.

Assess Literature and Staff Attitudes

Next, the team assembles the best evidence for FP by reviewing and critiquing related research, review and clinical articles, case reports, expert consensus statements, theory, and examples of EBP guidelines for FP that are shared and discussed with the staff. Staff beliefs and attitudes about patient-family–centered care and FP also should be assessed to determine baseline level of support. Various staff surveys, interviews, and open forums have been described [1,63], which can be adopted by institutions to elicit provider attitudes, concerns, and comfort level with patient-family–centered care and FP. The responses from such assessments can be used as a guideline for targeting strategies in overcoming institutional barriers and concerns and in developing an institutional-specific FP program. We have found that such activities heighten awareness about the topic and stimulate important debate and discussion among the staff [63].

Develop Family Presence Guidelines

The project team then drafts an EBP guideline or policy for FP based on the data gathered from the institutional assessment, expert professional guidelines, and results of research. It is likely that when FP is viewed within the context of best available evidence and is implemented according to an agreed upon structured process, many providers' fears about the practice will be diminished. Various FP guidelines have been published in the literature [1,21,63], which can be adopted for institutional use (Table 1).

Based on the best evidence, the ENA [1] recommends that written FP guidelines reflect a patient-family–centered care philosophy, a description of FP and the emergency situations and procedures involved, the process and principles of facilitating a FP event, and a delineation of the roles and responsibilities of staff and family members. Within the guideline, it should be clear that FP is an option for families rather than an expectation. The EBP guideline should reflect the role of the family facilitator (ie, a nurse, social worker, child life specialist, chaplains, clinical technicians) who has received special training in ENA's FP guidelines [1,64]

Table 2 Guidelines for family facilitator: support interventions.

After assessing the family member as an appropriate candidate for family presence and obtaining agreement from the direct care provider, the family facilitator will:

- Introduce yourself to the staff treating the patient and family
- Obtain information concerning the patient's status, response to treatment, identified needs
- Communicate known information concerning the patient's status to the family
- Use the patient's name when speaking to the family
- Assess the patient's and family's emotional and psychosocial needs and initiate measures to meet those needs
- Offer the option of bedside visitation to the family. (If family does not wish to be present they will be supported in their decision)
- Prepare the family for sights and sounds of bedside visit
- Facilitate family involvement and presence in accordance with the patient's and family's desire
- Assist the family members with making phone calls
- Offer and provide comfort measures
- Accompany the family to the treatment or resuscitation area
- When supporting the family at the patient's bedside, provide or assure the following:
  - Introduce yourself and other members of the support team to the family and patient
  - Explain the interventions and activities in the room
  - Interpret the medical/nursing jargon
  - Discuss information concerning the patient's response to treatment/expected outcome
  - Allow opportunities to ask questions
  - Facilitate opportunities to see, touch, and speak to the patient prior to in-house or outside transfer
  - NEVER leave a family member unattended at the bedside during resuscitation
  - Escort families out of the room if necessary
  - Participate in evaluation of staff and own emotional needs. Assist in identifying need for critical incident stress debriefing, individual defusing of events, etc.
- If death has occurred, a member of the Pastoral Care staff is responsible for and will coordinate the following:
  - Assure the family has been informed about what to expect, what they will see and hear
  - Facilitate the family's viewing of the body
  - Provide as much time as the family needs
  - Offer the family time alone with their loved one
  - Provide support during viewing, requests for tissue/organ donation, and requests for autopsy
  - Let the family know when it is OK to leave
  - Provide family with information concerning the disposition of the body, contact person, and phone number if they have questions later
  - Initiate, coordinate family bereavement follow-up at established intervals

The team leader or primary nurse will assist the family facilitator in identifying a medical or nursing liaison who may assist with clinical information, answering questions, and bringing the family into the treatment area.

Adapted with permission from *Presenting the Option for Family Presence*, ENA, 2001.

and dealing with families in crisis. Family facilitators first assess family members to determine whether they are appropriate candidates for FP to ensure that patient care is not interrupted. Families are not offered the option if they are assessed to demonstrate emotional instability, combative behaviors, or behaviors consistent with an altered mental status including alcohol or drug impairment or if they are involved in suspected child abuse [1,63]. After this assessment, the family facilitator obtains agreement from the physician (or direct care provider) for the visit and then offers the option of FP to the family member(s). If family members accept the option, the family facilitator prepares them for bedside presence, escorts them to the bedside to allow for visual and/or physical contact, and guides them through the experience. Should a family member become overwhelmed, he or she is escorted immediately from the area. If a family member declines FP, the person is supported in their decision and updated on the patient's condition and progress by the family facilitator. To assist in the education and training of staff, we recommend family facilitator guidelines (Table 2) [63].

When implementing a FP program, there are compelling reasons why EBP guidelines for FP are needed. Such guidelines establish the framework for best practice and provides a way of operationalizing and practicing a philosophy of patient-family–centered care that is responsive to patient-family needs. These guidelines represent best evidence, ensure consensus of thought about FP by key hospital leaders, and dictate administrative support and sanction of the practice especially related to adequate resources and staff needed to sustain the program. They assure that a structured plan is in place before critical decisions have to be made during a crisis to safeguard staff and provide equal consideration for all patients and their families. They delineate clear steps for who does what, when it should and should not be done, and under what circumstances to provide a consistent and safe approach to FP that is understood and carried out by all staff to achieve uninterrupted patient care. Moreover, such guidelines assure that educational programs are developed for staff, and a plan is created for ongoing research, evaluation, and quality improvement of the practice.

Evidence-based practice guidelines or written policies for FP exist rarely in hospitals, as documented in a recent survey of nearly 1000 critical care and emergency nurses throughout the United States [70]. Only 5% of these nurses worked on units that had written guidelines allowing the option of FP during CPR and IPs, although more than half brought families to the bedside during such events and many have been confronted with requests by family to be present [70]. It is recommended that nurses work closely with physicians and healthcare administrators to adopt more widespread written guidelines and policies supporting family access during emergency procedures [52,53,70].

Table 3 Summary recommendations

Guidelines for Providing Family-Centered Prehospital Care Consensus Conference, National Association of Emergency Medical Technicians, Clinton, MS, 2001

1) *The safety of all team members, including family members, must remain a primary concern during prehospital care and transportation*:
   Patient and team safety must always take precedence. Establish and follow local guidelines for scene safety on all calls. Assure that all vehicle occupants wear appropriate restraints whenever possible. Assure that movable equipment is secure during transport. When appropriate, provide family members who will drive themselves with directions including the need to obey traffic laws. Provide the National Highway Traffic Safety Administration-Emergency Vehicle Operator Course (NHTSA-EVOC) to all persons with ambulance driving responsibilities. Provide a map to the receiving facility that shows parking, how to find their family member, and phone numbers in case they get lost.
2) *Family members should be involved in primary training for prehospital emergency medical responders at all levels*:
   Use customer feedback programs to identify experienced local EMS consumers including not only patients but parents, siblings, and other family members with interest in sharing their experiences. Work with the local primary care community to identify families of children with special health care needs in your community that are potential EMS consumer-educators. Involve local Hospice programs and organ procurement programs in continuing education programs. Encourage local EMS training programs to incorporate family-centered care practices into their elective curriculums.
   Teach EMTs at all levels the value of family participation, both for themselves and families. Seek family member participation on policy development committees.
3) *Family members should be given the option to be present and to participate in prehospital care, on scene, during transport, and during transfer of care to the receiving facility*:
   Provide options whenever possible. Allow the family to remain with the patient during transport whenever possible. Use the family as a source of assistance to patient care by having them provide information (pertinent history, special developmental concerns, normal state of consciousness, dominant hand, best known IV site, etc.) and comfort (hold the patient's hand, sing a favorite song, or comfort the child during procedures). Introduce the patient and the family to the health care professional receiving the patient and identify a transition team member to the family. Encourage the family to be present for the report. Say goodbye to the family. Debrief them with clear, honest dialogue.
4) *Family-centered care practices, including family presence and cultural proficiency, should be integrated into the fabric of prehospital care everyday on every call*:
   Identify a team member to interact with family members on each call. Make eye contact when speaking. Identify yourself by name and ask patient and family members how they would like to be addressed. Use courtesy titles (Mr., Mrs., etc.) and avoid slang terms. Plan ahead to overcome language barriers, ideally without relying on children as interpreters. Communications should be a matter of routine that is consistent and constant throughout the incident. Explain equipment and procedures in clear, factual terms avoiding jargon and technical terms; do not assume that family members cannot understand explanations. Watch for verbal and nonverbal cues from families about the amount of information they want and whether they understand what you are telling them. Know that it is acceptable to say "I don't know" but follow that answer with "we will do everything we can to reach the best possible outcome for your child." Acknowledge feelings, offer support (how can I help you?) and express empathy when appropriate. Allay guilt by calling attention to something the family has done right. Maintain a calm professional demeanor; avoid matching emotional responses from family members. Avoid confrontations with other health care providers in the presence of patients or family members.
5) *Programs to better prepare families to deal with emergencies should be developed, assessed and replicated*:
   Identify and visit families of children with special health care needs in your response area. Provide the *Emergency Information Form* (EIF) and encourage its use. Develop protocols that address how to deal with in-home equipment and procedures that are outside your scope of practice. Develop policies on advanced directives for withholding or terminating prehospital resuscitation efforts. Develop procedures to effectively communicate with culturally diverse segments of your community including the presence of interpreters.
6) *An effective family-centered prehospital care program should include an established critical incident stress management program*:
   Establish a program to maintain employee mental health and manage critical incident stress. Know your own limitations; personalizing care, especially for critically ill children increases stress. Learn and recognize the signs of stress. Physical signs include fatigue, insomnia, nightmares, exhaustion, headache, and digestive disorders. Cognitive signs include flashbacks, difficulty concentrating or solving problems. Emotional reactions include fear, guilt, depression, anger and over sensitivity. Know that these are painful but normal reactions to stressful events. There are things you can do to feel better: exercise, talk to someone, alternate periods of activity with inactivity, continue making day-to-day decisions but avoid major life change decisions, treat yourself to something, avoid alcohol. Seek assistance from your organization's critical incident stress management team or mental health professional.

Pilot Evidence-based Practice Guideline to Evaluate Process and Outcome

After development of the EBP guideline for FP, the project team identifies the unit or units to pilot test and evaluate the guideline [65]. Multidisciplinary staff from the pilot units should receive a customized educational

Figure 1 Emergency Medical Services for Children continuum of care.

program grounded in principles of patient-family–centered care, an overview of the FP program and related EBP guidelines, and education about staff roles, responsibilities, and skills related to who does what and when to support patients and families during a FP event. In addition, process and outcome parameters are identified for the EBP guidelines, shared with staff, and used to evaluate the feasibility and efficacy of implementing the guideline in clinical practice [65].

Mangurten et al [63] used this model to evaluate process and outcome data related to a new FP policy during 65 FP events in a pediatric emergency department. The evaluation included an assessment of whether the new policy was correctly implemented (eg, were family members screened for FP, were family members assessed to be appropriate candidates for FP before being taken to the bedside, was the physician in charge informed of and in agreement with the option of FP, did family facilitators prepare family members for the FP event and stay with them during the event, what percentage of family members was deemed inappropriate candidates and what were the reasons they were not offered FP, what percentage of families declined the option of FP). Outcome data also were evaluated during these FP events to determine whether the presence of family at the bedside affected patient care (eg, were family members disruptive during the FP event, did they impede the operations of the medical team during the emergency procedure, did family members need to be escorted out of the room during the event and what were the reasons, and was patient care interrupted because the family was there).

After the pilot evaluation, a decision is made whether to adopt the practice [65]. If the pilot evaluation reveals feasibility and positive outcomes, the practice is adopted and integrated throughout the institution. Based on the results of the pilot evaluation, however, the EBP guideline may need to be modified before adoption. For example, in the Mangurten pilot evaluation [63], family facilitators reported that they were not comfortable and believed it was not in the child's best interest to offer the option of FP to parents suspected of child abuse. Thus, suspected child abuse was added to the policy as a contraindication for FP. After instituting the EBP guideline in practice, outcomes should continue to be monitored [65].

Family Presence in the Prehospital Environment

The federal EMSC program has for more than 20 years defined the scope of its activity through the conceptual model known as the *continuum of care* [71]. This classic model acknowledges the progression and related connectedness of emergency response, prehospital care, definitive hospital care, rehabilitation, and finally, return to the community in framing an approach to specific EMSC issues (Figure 1).

Patient-family–centered care and, specifically, the role of FP has clearly been an issue-specific area of interest for pediatric emergency medicine and EMSC as evidenced by the solid body of research and scholarly activity described in the manuscript. There has been much recent investigation focused on FP in the definitive hospital care phase of the EMSC continuum (ie, the emergency department and resuscitation bays) [2,13,21,27,31,63,72,73]. However, there remains a paucity of published information expressly addressing FP from the standpoint of the prehospital environment [74]. The most definitive work is theoretical and was undertaken by the National Association of Emergency Medical Technicians in collaboration with the federal EMSC program as a consensus conference to develop guidelines for patient-family–centered prehospital care. The conference was held in 2000, its proceedings synthesized by the panel of invited experts and posted as an EMSC Partnership for Children federal product in 2001 [75]. Although not specific to FP, the guidelines and accompanying discussion represent the most comprehensive effort to date to extrapolate the work heretofore confined to the hospital/emergency department setting to the prehospital arena. The specific recommendations generated through this process are summarized in Table 3.

There are many inherent and infrastructural challenges to the ready application of the FP principles espoused for the emergency department to the prehospital setting. The clinical and physical environment is less controlled, the

level of personnel present and/or available at a given scene is variable and inconsistent, and the EMS vehicle design, ground or air, typically limits direct patient access to the medical caretakers during transport. Nonetheless, awareness of FP is beginning to creep into the education and training sphere for prehospital providers [76], and it behooves organized EMS leadership to seriously engage hospital-based clinical investigators to extend their thinking proximally along the EMSC continuum of care back to the prehospital environment. There may be clinically advantageous synergy or the barriers may prove preclusive; regardless, FP in EMSC cannot be considered holistically explored until application in the prehospital arena is scientifically evaluated.

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