Pediatric emergency mass critical care: Focus on family-centered care

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**Introduction:** Pediatric emergency mass critical care during disasters requires modifications to standard healthcare operations. Modification of standards for pediatric emergency mass critical care should include incorporation of family-centered care principles. Family-centered care, which is an integral aspect of current pediatric practice, encourages active participation of the child’s family in medical care delivery. While family-centered care should be practical in most disasters, whether we can operationalize it in pediatric emergency mass critical care is unknown. However, every effort to adhere to the principles should be made. This manuscript addresses some of the basic tensions that exist between creating efficient disaster-related standards and offering family-centered care by augmenting the concepts outlined elsewhere in the supplement with practical suggestions on incorporating family-centered care. In addition, this manuscript demonstrates how family-centered care benefits not only children and families, but also the staff providing care to pediatric patients in disasters.

**Methods:** In May 2008, the Task Force for Mass Critical Care published guidance on provision of mass critical care to adults. Acknowledging that the critical care needs of children during disasters were unaddressed by this effort, a 17-member Steering Committee, assembled by the Oak Ridge Institute for Science and Education with guidance from members of the American Academy of Pediatrics, convened in April 2009 to determine priority topic areas for pediatric emergency mass critical care recommendations.

Disasters are characterized by an acute escalation in the demand for resources that overwhelms available systems. As such, disasters require modifications to standard operations. In conventional pediatric care, all resources are accessed to provide the best care for the individual child. In pediatric emergency mass critical care (PEMCC), the scarcity of resources mandates a consideration of decisions on the basis of their potential benefit for the majority rather than the individual. Despite daunting competing interests, family-centered care (FCC) should be considered and incorporated as much as possible during PEMCC events. While FCC is achievable in most disasters, such as the 2009 Influenza A/H1N1 Pandemic, it is likely to be far more difficult to incorporate into PEMCC events. In the absence of experience with actual PEMCC events, models predicting the need for tripling of pediatric intensive care unit (PICU) capacity and prioritization of life-saving events while foregoing or delaying less urgent care are helpful for planning. It is unknown to what extent FCC can be incorporated into PEMCC.

Steering Committee members established subgroups by topic area and performed literature reviews of MEDLINE and Ovid databases. The Steering Committee produced draft outlines through consensus-based study of the literature and convened October 6–7, 2009, in New York, NY, to review and revise each outline. Eight draft documents were subsequently developed from the revised outlines as well as through searches of MEDLINE updated through March 2010. The Pediatric Emergency Mass Critical Care Task Force, composed of 36 experts from diverse public health, medical, and disaster response fields, convened in Atlanta, GA, on March 29–30, 2010. Feedback on each manuscript was compiled and the Steering Committee revised each document to reflect expert input in addition to the most current medical literature.

**Task Force Recommendations:** This paper offers a list of practical suggestions for incorporating family-centered care principles into each of the following healthcare settings during a disaster, including a pediatric emergency mass critical care event: emergency medical services transport, emergency departments, pediatric intensive care units, general pediatric wards, and alternative sites. Disaster and pediatric emergency mass critical care responses must incorporate family-centered care principles to the extent possible in a variety of healthcare settings. (Pediatr Crit Care Med 2011; 12[Suppl.]:S157–S162)

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FCC is an integral aspect of current pediatric practice. FCC is defined as “an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families”. Patient- and family-centered care applies to patients of all ages, and it may be practiced in any healthcare setting” (1). In pragmatic terms, FCC encourages the active participation of the child’s family in the delivery of medical care to the child. FCC not only improves the healthcare experience of children, but also can reduce anxiety in healthcare providers who may be less familiar with the psychosocial and developmental aspects of pediatric care.

When planning for a PEMCC event, one needs to acknowledge the fundamental precepts of FCC as well as address some basic tensions that exist between PEMCC standards and FCC. For example, a necessary element of current PICU care is that physicians spend appropriate amounts of time discussing bad news with families. In a PEMCC event, these sensitive discussions may be facilitated by psychologists or other caregivers while the physician tends to the medical needs of other critically ill children. This example highlights the dilemma of FCC in PEMCC incidents: how do we both support the family and save the lives of as many children as possible?

It is clearly in the best interest of children to have their social, emotional, and physical support structures remain intact during periods of extreme stress. It is certainly in the best interest of families to remain engaged in their children’s care at a time when their children have such great need. Overwhelmed personnel and systems attempting to provide care for children in PEMCC may also benefit because families are a highly effective means of providing an increased level of assessment and care for injured and ill children. Hospitals may consider the family as a valuable deployable resource for ill and injured children during periods of surge and altered standards of care.

The following sections review the various potential healthcare systems that will be charged with caring for children in PEMCC and the opportunity for incorporating elements of FCC to promote optimal outcomes. They will address some of the fundamental concepts of FCC as well as raise awareness of important ethical considerations that both disaster planners and caregivers will face in a PEMCC event. This manuscript highlights practical suggestions for the implementation and maintenance of FCC during a PEMCC event.

**Basics of FCC and the needs in PEMCC**

Providing the best possible care for children in PEMCC requires incorporating elements of FCC. This orientation will help focus PEMCC readiness and response around the needs of children and their families, and will also supplement the knowledge base of nonpediatric professionals on the concept, principles, and applications of FCC.

In routine pediatric practice, FCC aims not only to involve the child’s parents in day-to-day management and care but also to ensure that standard policies and procedures take into account the needs and rights of families. Examples include:

- Encouraging families to “room in” with their hospitalized children.
- Allowing parents to be present for medical procedures (e.g., lumbar puncture, bone marrow aspiration, venous access).
- Encouraging participation by family members on daily bedside rounds.
- Respecting the family as a cohesive unit and the constant in a child’s life.
- Designing facilities and work flows that support families (e.g., family laundry, family library).
- Acknowledging cultural norms that support a child and his/her family.
- Supporting and facilitating family choices relating to therapy for their child.
- Supporting ongoing efforts, such as Family Advisory Councils, to assist the healthcare organization in their efforts and allowing families a “voice” in organized medicine.

The fundamental concepts of FCC have been embraced by pediatricians, hospitals, pediatric clinics, and support organizations for many years. These professionals report that a comprehensive approach to pediatric management that attends to the well-being of the whole family leads to better outcomes for medical care.

In normal circumstances, pediatric practitioners spend a great deal of time with families, explaining procedures and assessing a child’s developmental ability to understand and cope with an illness. In most pediatric centers, child life specialists augment staff interactions with families, providing education, counseling, and support to caregivers, siblings, and family members. It is highly unlikely that this construct will apply in a PEMCC scenario.

Preparation for a PEMCC incident requiring critical care of children first mandates a cogent approach to the acute medical needs of children, and these concepts are covered elsewhere in this supplement. This does not, however, preclude incorporation of FCC into PEMCC. Because of the unique vulnerabilities of children to the physical and emotional effects of disaster, they are likely to be more severely injured in greater proportion than adults (2). In the setting of increased need for care and limited personnel, engaging the family and caregivers augments available resources as well as provides a level of expertise on the child’s well-being and condition.

**Emergency medical services and the care of children**

Since the advent of the National Emergency Medical Services (EMS) for Children program, emergency caregivers from across America have sought to improve the care rendered to children during emergencies. EMS for Children grants have funded research in the areas of transport, regionalization, and emergency department (ED) equipment norms. Likewise, the fundamental concepts of FCC are emerging as part of routine care for EMS systems. For example, allowing a family to stay with a child during resuscitation and stabilization, once thought unacceptable, is now part of standard procedures in many EMS protocols.

During a disaster, EMS professionals are expected to handle many competing issues. The institution of mass casualty triage, securing the scene, establishing a disaster command center, and arranging physical transport of the ill and injured all must be implemented quickly and professionally. In the case of a pandemic, EMS systems will be taxed with the added burden of understaffing, inadequate resources, and concerns for infection control. Despite the intense demands of healthcare provision to children in these settings, the needs of the family also must be considered and addressed. Obviously, tension and ethical dilemmas can exist when dealing with a PEMCC event. Perhaps the biggest dilemma facing EMS...
providers, in both daily operations and during disasters, is to separate a child from the family to facilitate medical care. For instance, several severely injured/ill children may need to be transported together by the most qualified EMS providers, thus precluding parents from accompanying their children to the treatment site. In a pandemic, family separation will likely occur in the necessary processes of infection control.

Considering these dilemmas coupled with the objective of directing as much attention as possible to children’s and families’ needs, the following practical suggestions have been developed for EMS professionals planning for and responding to mass casualty/pandemic events that involve children (3):

- Encourage family participation in the establishment of pediatric care guidelines and disaster preparedness guidelines.
- Encourage local pediatricians to work with families to plan for disasters, including preparation and storage of disaster ration and disaster kits, and storage of important medical information, such as medical history and medication lists.
- Encourage local groups to champion family preparedness for disasters.
- Establish policies that allow families to remain with their children when practical during emergency care.
- Develop resources for non-English-speaking families.
- Identify one professional on scene whose responsibility is family communication and updating.
- Establish relationships with local pediatricians and hospitals before an emergency/crisis to identify children with special healthcare needs in advance.
- Develop FCC educational sessions for emergency medical technicians and paramedics.
- Collaborate with local disaster resources, such as the Medical Reserve Corps and disaster medical assistance teams.

Prehospital and EMS care of children in mass casualty/disaster events poses specific threats as well as opportunities for FCC. The proactive institution of training, protocols, and guidelines for FCC is likely to have the greatest impact on facilitating optimal care of children by prehospital providers.

**ED care of children in a mass event**

During a PEMCC event, EMS and ED resources will be overwhelmed. Rigorous preparations for emergencies that affect children can mitigate the effects of a disaster on children. In a recent survey of nonpediatric EDs, only 4% carried all of the recommended equipment for pediatric emergencies (4). EDs cannot adequately deal with hundreds of ill and injured children if equipment is not available for the day-to-day care of one critically ill or injured child.

To that end, the American Academy of Pediatrics has published guidelines for nonpediatric EDs (5). One of the most important recommendations is for nonpediatric EDs to engage a pediatric expert. This clinician (physician, nurse, etc) would not only serve as the “go-to” person for pediatric planning, but would also help establish and refine relationships with local pediatric resources, such as children’s hospitals and pediatric offices.

All hospitals, even those in close proximity to pediatric specialty hospitals, must be prepared to care for children in a PEMCC event. Local and regional children’s hospitals will quickly be overwhelmed, and thus the need for ED, inpatient ward, and alternative-site care of children will become paramount. It is predicted that some 80% of patients will transport themselves to a “closed” or overwhelmed facility during a disaster.

As difficult as it may be for local EDs to be prepared for disasters affecting children, the ability of these facilities to practice FCC during such as mass event is even more challenging. Overcrowding, panic, security concerns, staff stress, and separation of families during triage make practicing FCC an imperative but demanding task. The fundamental precepts of FCC, such as attention to the family as a unit, respect of parental rights, and assessment of the health of the entire family unit, remain critical to the success of disaster management. The following are some high-level recommendations for ED professionals as they plan and respond to the needs of children and their families in a mass event. Planners are also referred to an excellent resource prepared by the American Academy of Pediatrics, “Pediatric and Family-Centered Care and the Role of the Emergency Physician Providing Care to a Child in the Emergency Department” (6).

**Triage and Stabilization**

1) EDs should participate in mass casualty drills and become familiar with pediatric-specific triage tools.
2) EDs should be prepared to care for large numbers of children with very short notice. Some adult triage tools and EMS workers unfamiliar with pediatric patients may overtriage children to the more serious colors (RED, life-threatening injury requiring immediate attention; or GREEN, serious, but not life threatening) rather than yellow, which signifies minor injuries.
3) When possible, EMS and EDs should allow a parent to remain with the child during the triage and stabilization process.
4) Families’ knowledge of their children, especially children with special needs, should be recognized as important when treating the child. The family is often in a better position to diagnose emergent conditions than the healthcare providers.

**Family Reunification**

1) As soon as possible, EDs should work to reunite separated families.
2) The local triage and intake tools should allow for a digital photograph and should employ a standardized method of collecting identifying information, including at least name, gender, ethnicity, eye color, and date of birth.
3) The National Center for Missing and Exploited Children (www.missingkids.com) is designated by the government as the appropriate agency to assist with reuniting families in a mass disaster. It is important that identifiers be obtained as quickly and accurately as possible to assist this agency. Policies and procedures of reunification, as developed by the National Center for Missing and Exploited Children, clearly have applicability in the event of mass critical care disasters.
4) Issues of appropriate methods of identification, temporary surrogate caregivers, and privacy of information have already been addressed by the National Center for Missing and Exploited Children.

**Family Support**

Identifying an area outside the ED for families to wait is essential. This area can be staffed with social workers, mental
health workers, and volunteers, and should be stocked with appropriate resources.

Consent for Procedures

1) Emergent life-sustaining procedures may be performed despite the inability to obtain consent.
2) Nonemergent procedures will likely be delayed in the attempt to treat large numbers of children with life-threatening conditions. However, when indicated and available, these procedures require consent.
3) Nonemergent procedures to mitigate or alleviate pain or suffering can reasonably be implemented in the absence of consent. For the benefit of all involved, policies for this altered standard of care under disaster conditions should be vetted and in place at all institutions.

Transport to Tertiary Care

1) EDs should work with local pediatric resources to develop transfer agreements before a disaster strikes.
2) EDs should also preidentify multiple modes of transportation that can be engaged in a crisis.

Assessment of Mental Health Needs of Children and Families

1) Children are far more vulnerable to traumatic events and are at greater risk for emotional, social, and mental health problems than are adults. The more quickly the child is reunited with the family, the better the outcome for the child.
2) Mental health professionals trained in triage and emergency treatment of children should be available on scene.

Pediatric critical care

Critically ill children in a PEMCC event will be housed in the PICU and other areas deemed suitable when the PICU capacity is overwhelmed (see the article, “Treatment and triage recommendations for pediatric emergency mass critical care”). These children have severe and complex physiologic derangements; however, the need to triple PICU capacity in PEMCC will result in altered levels of care. Psychological stress and trauma have been well documented in PICU patients and their families even under optimal conditions (7) and may be exacerbated under disaster scenarios. FCC can be implemented in a manner analogous to the ED issues outlined earlier (e.g., reunification, triage, and family presence during procedures).

However, the challenges to the delivery of FCC during a PEMCC event are legion. Staff and resources will be inadequate to meet all demands of medically unstable children, leading to increases in morbidity and even mortality that are avoidable under more routine conditions. The dearth of life-sustaining medical equipment will require resource triaging in a manner that strives to provide the best outcomes for the largest number of patients, rather than the allocation of numerous resources to a few critically ill children. Some children currently managed in PICUs would likely be deemed ineligible for further support under PEMCC triage conditions. The process of deciding to terminate or deny support to a child and the conveyance of that decision to the child and family is a challenge and stress to the healthcare team. The relationship between families and healthcare providers could become confrontational since the families view the physicians as ultimately responsible for the decision of whether or not their child is to receive assistance.

Healthcare providers will be compelled to focus on the stabilization and improvement of serious medical conditions. The contemporary role of physician as the “team leader” in the multidisciplinary model of health care includes arranging and leading family meetings and discussions on multifaceted aspects of patient care. This is a practice that is likely unsustainable in a PEMCC scenario. The designation and clear identification of a “family liaison contact,” such as a social worker, child life specialist, or nursing assistant, to gather and disseminate general information of interest to families could reduce demand on the highly trained and skilled medical personnel attending to the acute needs of critically injured or unstable patients. Since the liaison’s role would be the dissemination of general information, they would not need clinical training but could be briefed at the scene on resource availability and locations, strategies for reunification, and similar issues.

In many areas of the world, families provide direct medical care to critically ill children. Administration of resuscitation fluids orally and via nasogastric tube, hand bagging of ventilated children, and wound care are commonly performed by families in areas of the world with very limited resources. Families are extremely motivated learners of these skills and can be highly effective providers of even high-acuity care.

In summary, the pressures on critical care resources during a PEMCC event will be extraordinary. Through proper planning and constant assessment, it is hoped that the fundamental principles of FCC could still be employed under these circumstances.

General pediatric wards

In PEMCC events, general pediatric wards and other high-dependency areas may also be overwhelmed with caring for critically ill children. Plans must be designed not only to “flex-up” space and resources for hospitalized children, but also to ensure that families are informed of all care decisions as well as supported as a family unit. The following topics should be considered:

Family Support

1) Provide a general area for families to “room in” with their child when possible – this may have to be limited to one family member in circumstances where space is at a premium.
2) Include families in daily care plan development – once again, while this is a basic tenant of FCC, caring for massive numbers of ill or injured children may call for either abbreviated rounds or unique models of care where family inclusion may be more difficult.
3) Employ a family liaison – most pediatricians spend countless hours discussing diagnosis and treatment with families, but in a mass care incident, a designated “family liaison” may be charged with family communication. While this is far from ideal, the skills and knowledge of physicians and nurses may be better utilized in providing direct care.

Consent

1) As much as possible, families should still provide consent and be advised of the risks, benefits, and alternatives to a particular procedure. However, in extreme circumstances, “disaster standards of care” may dictate a surrogate to provide the medical rationale and risks/benefits while the physician and nurse provide direct care.
2) A more in-depth discussion of the ethics of consent in disasters can be found in the consensus paper on ethical considerations (see the article,
Alternate sites

In major disasters, hospitals and clinics will fill quickly, and as a result, ill and injured people will likely have to be cared for in other locations, such as churches, community centers, and schools. Some of these alternative sites may also be used to provide shelter for those who may not be ill or injured, but who have lost their homes or become separated from family members. To assist in the selection of alternative sites, predisaster community planning should include identification of community leaders familiar with community needs and resources. These could include support staff from pediatric practices, teachers, school support staff, and others. Ideally, potential alternative sites will not only preplan for the basic needs of children and families (shelter, food, water) but will also review the basic precepts of FCC and plan accordingly. Paramount in preparing these sites is child safety, which requires that volunteers have background checks. Planning should include a mechanism for reuniting children with families and proper supervision for children.

Obtaining a Medical History. In the case of a disaster that adversely impacts children, it is crucial to remember that children may be too young to speak for themselves or too traumatized physically or emotionally to speak for themselves, and so the presence of a family member is essential. In the absence of a trusted family member or family friend, disaster centers should be prepared for both language barriers and growth and development barriers to communication. A recommended tool to assist disaster centers in collecting information on medical history and current symptoms is a laminated card with the following: common phrases and questions in a number of languages; pictograms showing body parts so a child can point to where something hurts; pictures of facial expressions to enable children to communicate comfort or pain; and charts showing normal growth and development levels for children (8).

Information about the child’s normal routines is helpful because approximating these routines while providing care will lend a sense of normalcy and provide a safe context for the child to cooperate with medical caregivers. This strategy has been shown to help children recover. Children’s personal preferences on how they are best comforted should also be noted.

Strategies to Reunite Families. Reuniting families as soon as possible should be a very high priority. At alternative sites, space should be provided for families to be together, or at least for families to stay nearby. Reuniting families is very important and the presence of family members has been shown to be critical in ensuring patient safety.

When families are reunited, parents (or other family members) should be given some guidance on what to expect from their children in terms of psychological reactions to the disaster and to the separation from family. Signs or symptoms to watch for that might require attention and/or intervention should be described, along with suggestions of how to provide appropriate support following the disaster.

Establishing Lines of Communication When Families Are Separated. During the severe acute respiratory syndrome experience in Toronto, staff worked very hard to try to keep families in touch with one another. This type of effort requires a tracking system, such as a computerized database, to identify who is where and how they can be contacted. Once locations are known, all routes of communication should be engaged—hand-delivered letters, drawings, and photographs; computer greetings (letters and photographs); Skype and telephones, for example.

Welcoming the Presence of Family Members at Alternative Sites

Accommodations. In maintaining a patient- and family-centered model of care where the family unit is intact, caregivers should address the need to provide some level of on-site accommodations for family members. Caregivers should view the term “family members” in the broadest sense possible because the child may not be part of a traditional family unit. Furthermore, one or both parents may be ill, injured, or missing so another relative or friend may be called upon to provide support. Because the disaster site may be crowded and not well suited for accommodating family members, caregivers need to be creative and open to ways in which this can be done. For example, if the alternative site is a school and space is not available beside the bed/cot for a family member to sleep, caregivers should consider the use of other venues nearby, such as an auditorium.

Communication and collaboration with family members who are present. Every effort should be made to keep lines of communication open with family members in ways that are useful and affirming. They should be viewed as partners in care and patient safety. In fact, no one is better able to advocate for a child than a family member who knows his or her child’s health history and physical and psychological needs. Further, in disaster situations, staffing shortages may well exist so that family members can provide needed support to staff as well.

Privacy. Sensitivity to privacy needs can be met by using portable screens or sheets between cots as needed and by providing additional privacy for terminal care. Staff may need to consider the use of alternative sites within the nontraditional building in which they are providing care.

Cultural and linguistic differences. Disaster planning efforts should anticipate the need to support linguistic and cultural differences.

Supporting children’s normal growth and development. If care in alternative sites is expected to continue for several days and a family member cannot be present, someone, such as a child life specialist, should be tasked with providing play activities for the children.

Support Systems for Patients, Families, and Staff during Disasters. Because disasters are emotionally taxing experiences for all concerned, psychological counseling should be available for all patients, families, and staff.

CONCLUSIONS

The prospect of caring for large numbers of critically ill or injured children is daunting for most healthcare systems. This section has attempted to augment the cogent preparations and plans outlined elsewhere in the supplement with practical suggestions for planners and responders. Likewise, one should be reminded of the key importance of planning for the needs of families and supporting PEMCC events. This approach will not only support high-quality, evidenced-based care, but will also support the needs of the “whole child” and family in crisis.

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