

EMSC-Partnership for Children



**National Association of
Emergency Medical Technicians**

**Guidelines for Providing
Family-Centered Prehospital Care**



Executive Summary

A two-day Consensus Panel Meeting on Guidelines for Family-centered Prehospital Care, hosted by the National Association of Emergency Medical Technicians through a contract from the Health Resources and Services Administration's (HRSA) Emergency Medical Services for Children Program was held in Washington, DC on July 24-25, 2000. The panel represented 17 stakeholder organizations plus family and cultural competency representatives. The goal of the meeting was to recommend guidelines for Family-Centered Care Practices in the prehospital setting including family presence during out-of-hospital care and transportation of children, safety of children and family members during transport, enhancing skills for communication with family members and dealing with prehospital healthcare provider stress issues.

Several panel members made brief presentations of related topics and then led group discussions about their topics:

Tommy Loyacono, MPA, EMT-P, presented the group with copies of a Literature Review that was prepared for the meeting and presented a summary of its findings.

Kate Shaner, RN, EMT-B, led a discussion about techniques for communicating with families during prehospital treatment and transportation and about the benefits of family presence during prehospital care.

Linda Eckfeld & Ruth Le Blanc, presented their personal stories as parents who have interacted with prehospital professionals during the deaths of their children and led a discussion about parental needs during prehospital care and transportation.

Kim Bullock, M.D., gave a presentation on cultural competency and described various ways that cultural differences affect access to and delivery of prehospital care.

Don Lundy, EMT-P, led a discussion about how prehospital care is similar to, yet different from other aspects of emergency care focusing on challenges that are unique to the prehospital environment.

Stacy Denicola, EMT-P, presented an overview of critical incident stress management in the prehospital setting and led a discussion on the topic.

Following the group discussions the panel made the following recommendations:

- The safety of all team members, including family members, must remain a primary concern during prehospital care and transportation.
- Family representatives or organizations [members?] should be involved in primary training for prehospital emergency medical responders at all levels.
- 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
- Family-centered care practices, including family presence and cultural proficiency, should be integrated into the fabric of prehospital care everyday on every call.
- Programs to better prepare families to deal with emergencies should be developed, assessed and replicated.
- An effective family-centered prehospital care program should include an established critical incident stress management program.

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The healthcare field is evolving from a paradigm where the patient is expected to passively comply with diagnosis and treatment to one that emphasizes patient-provider collaboration, and holistic health care. As part of this evolution, the concept of family-centered care has emerged. Family-centered care was first articulated in former Surgeon General C. Everett Koop's initiative for family-centered, community based, coordinated care for children with special health care needs and their families in 1987. Since then, the elements of family-centered care have been integrated into other areas of health care and human services. Family-centered care is a dynamic approach to building collaborative relationships between health care professionals and families and using those relationships to assist in providing quality EMS care and promoting overall health and safety in the community. Family-centered care recognizes the family's knowledge of one of their member's condition as an important tool to enhance quality of care and communication to the benefit of the health care team. It emphasizes the importance of communication and inclusion of the family as a member of the team: from incident site to prognosis and treatment. Family-centered care embraces the choices of families in the care of their members in the full spectrum of care, from presence during procedures to presence on committees and advisory councils designed to guide healthcare organizations and create public policy.

Comprehensive and effective emergency medical care of a child requires family involvement. Collaboration with families improves care and is helpful to providers when care is being delivered under difficult circumstances. To build a system of care that is responsive to the needs of children and families, emergency personnel need education and training that provides information and tools regarding how to best involve families during a medical emergency. To assess its status and encourage its development, the Maternal and Child Health Bureau (MCHB) contracted with the National Association of Emergency Medical Technicians (NAEMT) to develop guidelines for prehospital care providers related to implementing family-centered systems of care through collaboration with national organizations, communities and families.

Consensus Process

The NAEMT conducted a literature review to identify current family-centered prehospital care practices, barriers to adoption of family-centered care and potential solutions to the barriers. The NAEMT convened a consensus panel to consider these issues and draft guidelines for family-centered prehospital care. The draft guidelines were revised from public comment and the final guidelines will be disseminated through publication of this report and creation and distribution of a fact sheet on prehospital family-centered care. NAEMT will also submit an article about the Guidelines to a

national EMS journal for publication. Documents produced as a result of this effort will utilize definitions and terminology that is consistent with the EMSC Five-year Plan and other work sponsored by the EMSC Program.

Literature Review

The literature review revealed few published works that investigate family-centered care principles as they relate to prehospital care. Numerous studies have investigated parental presence during invasive procedures conducted in emergency departments; this body of research may be suggestive of parental and provider attitudes regarding parental participation during prehospital care as well.

The research that has been conducted suggests that emergency service providers often are responsible for death notification, and that they are able to do this competently. Transport services often have room for family members but do not make full use of this capacity. However, families that have participated in "ride-along" programs have favorable impressions of the experience, and there appears to be a low complication rate. The limited research into attitudes of family members concerning presence during invasive procedures and resuscitations in the emergency department suggests that families want to be given the option and when given the option, often choose to remain with the patient. Those that remain generally report favorable experiences and state that they feel it is beneficial to the patient and to themselves. Providers have mixed opinions regarding family presence, but the literature suggests that provider attitudes become more positive as experience with family presence programs increases.

The literature suggests that family members are often with the patient during the emergency onset and often assist in providing aid prior to EMS arrival. Family presence during the onset of prehospital resuscitation is likely, suggesting that the question of family presence may be moot for prehospital EMS. Rather, the question may be exactly how much the family members should participate. The question of presence during transport is a critical question that needs to be addressed. The entire literature review is appended to this document in Appendix A.

Consensus Panel Discussion

The NAEMT hosted a consensus meeting of family-centered care stakeholders to recommend guidelines for family-centered prehospital care. The two-day meeting was held in Washington, DC on July 24-25, 2000. Organizations represented at the meeting included the American Academy of Pediatrics, the American Ambulance Association, the American College of Emergency Physicians, the American Psychological Association, the EMSC National Resource Center, the Emergency Nurses Association, Family Voices of Tennessee, the Institute for Family-Centered Care, the Maternal and Child Health Bureau, the National Association of Children's Hospitals and Related Institutions, the National Association of EMS Physicians, the National Association of EMS Educators, the National Association of Emergency Medical Technicians, the National Association of Social Workers, and the National Association of State EMS Directors. In addition, there

were two parent representatives who have personal experience with prehospital EMS during critical interventions with their children, and a representative with expertise in cultural competence issues.

Following a review of the current literature, the consensus panel focused its discussion on five areas: communicating with family members during prehospital emergencies, family needs during prehospital care, cultural competency, issues unique to the prehospital environment, and the effects of family-centered care on prehospital providers.

Communicating with families:

Kate Shaner, RN, EMT-B, led a discussion about techniques for communicating with families during prehospital treatment and transportation and about the benefits of family presence during prehospital care. She described family-centered care as a philosophy of care and family presence as one piece of that philosophy, cautioning against confusing the two concepts as being synonymous.

Communication skills and the need to enhance communication with families dominated the meeting and infiltrated every agenda topic. The group recognized the need for simple, honest communication as a basic necessity stressing such topics as explaining the function of equipment, the procedures being performed and their rationale. Family members on the panel observed that not only do explanations serve to help keep people calm, information is needed so that family members can be better prepared to make decisions about care ranging from hospital destinations to termination of resuscitation.

Early in the discussion the group recognized that family-centered care principles represent a paradigm shift for prehospital care providers. Prehospital personnel are generally very motivated to do their best for their patients but lack training in how and why to communicate with family members. Their world is one of rapid, critical assessment and intervention, expedient transport, and transfer of care to in-hospital personnel. They generally see their role as relatively short-term patient care providers rather than a part of the entire care continuum. There was considerable discussion about ways to teach medical professionals the art of communicating with families and to assure that communication with families is integrated into the care continuum rather than seen as a separate procedure. Central to this goal is the need to show prehospital providers why family-centered care practices are a part of "good patient care" that can serve to make their jobs easier. Examples include: the potential to decrease patient and family member anxiety and combativeness by giving family members something tangible to do, may decrease liability issues if parents are part of the decision making process, and may aid in getting consents (especially for organ donation) if the parents are aware of everything that has been done.

With medicine becoming more customer driven, prehospital EMS personnel need to be taught not only how to communicate with family members, but the value of family presence. Some obvious values include the emotional benefit to the child and family member, improved access to medical history, and informed consent for procedures. The

group recognized that patients are not often individual entities. Because families are systems unto themselves, an emergency affecting one member affects all members. Perceptions about care delivery during prehospital emergencies permanently affect how family members perceive the critical event.

Expert input is necessary when teaching any skill. The panel recognized the expertise of family members who have interacted extensively with EMS in identifying what knowledge and skills are needed to effectively meet family member needs during prehospital emergencies. They strongly expressed the need to involve EMS consumer family members and family organizations in the initial training and continuing education of prehospital care providers of all levels if family-centered prehospital care is to become a reality.

Both the literature review and the group's experience seemed to verify that while most family members want the option to remain with an injured child and participate in care, they tend to be "self-limiting" with the degree to which they wish to be involved. Some family members do not want to remain during procedures and want to have minimal involvement. This should also be a family member's option and they should not feel pressured to participate in care beyond their own desire and ability.

Physical limitations imposed by vehicles, equipment, and crew size necessary to adequately care for the patient must also be considered. Though the option for family presence during care is desirable, it must never be allowed to interfere with the care of the patient or the safety of the crew or patient. Complications resulting from family presence and participation in prehospital care were recognized as minimal, and it was noted that like most skills, interacting with family members and talking through procedures becomes easier with experience and practice.

Pediatrics continues to represent only about ten percent of prehospital call volume and critical pediatric emergencies are an even smaller number. Thus, prehospital providers are least likely to be comfortable and experienced with these skills when caring for critically ill children. This strengthens the argument that family-centered care principles should become an integral part of EMS care that is practiced everyday on every call.

Family needs during prehospital care:

Linda Eckfeld & Ruth Le Blanc, presented their personal stories as parents who have interacted with prehospital professionals during the deaths of their children and led a discussion about parental needs during prehospital care and transportation. They, along with other family advocates in the group, re-affirmed much of what was previously discussed from the family point of view.

The actions of the health care professionals permanently impact family members well beyond the loss of a child. Often saying nothing and excluding families from being present is worse than inadvertently doing or saying the wrong thing. Simple things are often very important. Medical personnel should not be afraid to admit they don't have all the answers, but should assure that they will do the best they can to find the answers.

Family members want the option to be present and to participate in their family member's care without feeling obligated to participate beyond their level of comfort.

Medical personnel should not assume that parents are not capable of assimilating and coping with information about their child's condition. Being able to witness a child's care can help family members better cope with his or her death. One parent said it was much easier to believe the health care team had done their best when she was able to witness it first hand. Family members can also play an important role in care delivery because they know their children so well. Not only can they help keep the child calm through presence, touch, a song, or some other means, but they are also sources of clinical information such as best IV sites, normal states of consciousness, special developmental concerns, current medications etc.

The health care system needs to do a better job of preparing families for emergencies and critical events. Ways to improve family preparedness include injury prevention activities such as bike helmet and child car seat programs, improved discharge instructions, distribution of the emergency information form (EIF), and EMS interaction with families of special needs children before an emergency. Providing for the needs of family members during emergencies include organizing response teams of mental health professionals or specially trained paraprofessionals to support family members at the scene of SIDS deaths, suicides, or other fatality incidents where these services might be beneficial or being prepared to provide access to these resources, and provision of bystander care programs. Provision should also be made to assure that trained, qualified personnel approach families about organ donation when appropriate. Discussions about donation should be conducted by persons trained in methods of obtaining consent and should be separate from, and subsequent to discussion of the patient's death.

Cultural competency:

Kim Bullock, M.D., gave a presentation on cultural competency and described various ways that cultural differences affect access to and delivery of prehospital care. She stressed the need to integrate cultural proficiency into the provision of health care rather than treating it as a separate set of skills. Illness and disease are not the same. It is important to keep in mind that patients may suffer from an illness, but not have a disease. The term illness is defined by cultural factors, perceptions, and labeling. It is tied to the social systems of what is defined as an illness experience.

Cultural competency is a set of values, behaviors, attitudes, and practices within a system, organization, program, or among individuals that enables them to work effectively across cultures. Cultural competence is a dynamic developmental process that requires a long-term commitment and is achieved over time. It goes hand in hand with family-centered care, and like family-centered care, must be achieved through integration into the fabric of EMS rather than attempting to add it as a new body of knowledge or a separate set of skills.

It is important for prehospital EMS providers to be aware of the various cultures residing in their response areas in order to be adequately prepared to serve them. Understanding family structure can be key to providing effective care and avoiding hostile reactions as a result of inadvertent disrespect toward family members. The traditionally subordinate role of children in a family structure can be reversed when children are used as interpreters. In certain cultural groups this can be seen as a threat to parental authority and thus present a barrier to care.

Cultural barriers to care go beyond mere linguistic barriers. Prehospital provider actions can affect patient perception of subsequent hospital care. Cultural biases can affect evaluation of certain patients. Some diseases are more prevalent among certain ethnic populations. Culture affects patients' beliefs concerning the nature, cause and extent of their illness as well as their perception of pain and acceptable treatments. Customs and beliefs often affect patient's willingness to use the health care system, including ambulance rides to the hospital.

Culture may determine whether patients come to the hospital at all, and whether they seek treatment early or late in their disease process. Culture may also affect compliance with care instructions.

Cultural competence begins with certain basic actions for all responders. Identify yourself, not only to the patient but to family members. Interaction with extended family can be key to obtaining needed information that the patient may not be able or willing to provide. Ask how the patient would like to be addressed; use courtesy titles. Do not become too informal and avoid the use of slang terms and jargon.

Unique prehospital challenges:

Don Lundy, EMT-P, led a discussion about how prehospital care is similar and different from other aspects of emergency care focusing on challenges that are unique to the prehospital environment. Prehospital care is similar to emergency department care in that it focuses on short-term interventions, more often interacting with families during their most stressful times. The traditional prehospital care paradigm is protocol-driven care that is often conducted without the benefit of medical records or support facilities. There is a need to identify ways to change the culture of prehospital EMS so that prehospital providers see themselves as a link in the health care continuum that affects the patient and the patient's family beyond the emergency department door.

Family involvement in education and buy-in from internal mentors are necessary components of effecting a shift toward family-centered care. Prehospital personnel need practical education and practice, including role playing to achieve competency in dealing with family members during emergencies without adversely affecting patient care. Prehospital care teams typically pre-plan duties on calls. Family interaction duties should be considered in this pre-planning activity. Partner arrangements should reflect teams with at least one "family-centered member." Family-centered care is personal and should not be scripted, but key phrases and actions should be identified, taught, and used. A training course is needed to help achieve these goals.

Family members should be considered an integral part of the health care team. Like other team members, they have a role to play in the care of the child during prehospital care that includes comforting the child, making decisions and consenting to procedures on behalf of the child, and providing pertinent information about the child to other health care team members. Prehospital care personnel should acknowledge this relationship and utilize family members to help improve patient care during on scene treatment, transport, and transition of care to in-hospital personnel.

The panel discussed cases of suspected child abuse or child neglect where the family member is suspect. It was noted that prehospital providers are mandatory reporters of suspected child abuse and should have operational policies in place to address this issue. Child abuse cases are among the most stressful cases for all health care professionals, however the test of professionalism is not to act out one's personal feelings. Be courteous and respectful despite the nature of the alleged abuse. Concentrate on providing proper care for physical injuries, thoroughly documenting any unusual behavior on the part of the parent/caretaker and informing hospital authorities of what was seen and heard at the scene.

Safety is a concern for all aspects of emergency care but is central to prehospital care because of the activities involved with transporting patients and family members by motor vehicles and aircraft often while providing highly technical interventions. The issue of safely transporting children by ambulance is the subject of a Maternal and Child Health Bureau (MCHB) Targeted Issue Grant; guidelines will likely follow. What is considered appropriate for passenger vehicles has not been proven to be appropriate for ambulances. Some guidelines for safe transport of children and families by ambulance include, cautious driving at safe speeds utilizing the National Highway Traffic Safety Administration (NHTSA) Emergency Vehicle Operator Course (EVOC) standards, securing all medical equipment whenever possible, and ensuring that all occupants are restrained whenever possible. Do not permit a child to be transported in a caregiver's lap or arms. If possible, do not transport non-patient children by ambulance. A related safety issue is family members who follow the ambulance to the hospital in their personal vehicles. Their safety needs to be considered as a part of an overall prehospital care safety program.

Prehospital provider stress issues:

Stacy Denicola, EMT-P, presented an overview of critical incident stress management in the prehospital setting and led a discussion on the topic. A critical incident is any incident that overwhelms the health care provider. It does not have to be a disaster; what causes stress varies among individuals. Critical incident stress management is an integrated system of services and procedures designed to prevent, mitigate, and assist in recovery from traumatic stress. It involves health care providers caring for each other. Personalizing care increases stress, and studies have shown that caring for critically ill children is among the highest stressors of prehospital care providers. A system for managing critical incident stress is essential when implementing

a family presence program. The use of critical incident stress management teams increased with the institution of family presence during invasive procedures in some institutions but tapered after health care workers gained experience with the program, suggesting that experience increases the health care professional's comfort with family presence during procedures.

Critical incident stress management requires a well-trained staff and the acceptance and encouragement of management at all levels. The team offers leadership and education about c.i.s.m. activities within an organization, but c.i.s.m. is the responsibility of the entire organization. Critical incident stress management programs should be peer driven, offering a "safe place" for health care providers to deal with stressful issues. Once a program is in place and functioning properly it serves as a stress prevention tool. Staff becomes familiar with the signs of stress and what actions to take. In many cases they are able to "self treat" thus avoiding long-term ill effects of stress by keeping small problems from becoming larger ones.

A current MCHB contract with the American Psychological Association is evaluating prehospital critical incident stress management programs. Recommendations developed from that contract will be forthcoming and should be considered when developing programs for critical incident stress management.

Recommendations

The consensus of the panel can be summarized in six recommendations for implementing family-centered prehospital care.

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.

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.

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.

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 non-verbal 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.

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.

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.

References

The panel felt it was important to include references pertinent to the principles of family-centered care, family presence, and cultural competence in its report. References identified by the panel members as especially useful for these topics are as follows:

Cultural Competency References:

- Developing Cross-Cultural Competence by Eleanor W. Lynch and Marci J. Hanson
- Culture-Centered Counseling Interventions Striving for Accuracy. by Paul B. Pedersen
- Ethnicity and Family Therapy by Monica McGoldrick, J Giordano, JK Pearce.
- Assessing and Treating Culturally Diverse Clients by FA Paniagua.
- Culture in Clinical Medicine by RF Hill, DJ Fortenberry, and HF Stein.
- Adolescence as a Culture-Bound Syndrome by RF Hill, and DJ, Fortenberry.
- Adolescence and Old Age, Part 2: Medicalization and Medical Specialists by RF Hill, Otto von Mering, and Elizabeth A Guilty.

Critical Incident Stress Management References:

- Critical Incident Stress Debriefing by Jeffrey Mitchell and George Everly

Family-Centered Care References:

- Working with Families to Enhance Emergency Medical Services for Children, by BH Johnson, J. Thomas, and K Williams (available on-line at www.ems-c.org)

Directions for Future Study

Research related to family-centered care in EMS is scarce. Little is known about family attitudes regarding presence during procedures and resuscitations in the field. Prehospital provider opinions and practices related to family-centered care should also be studied. EMS systems should be surveyed to determine the extent to which families are represented on advisory councils, committees, and panels that influence practices, training, and curriculum coordination. Larger studies need to be conducted on the communication skills of emergency service providers including family satisfaction with the amount, content, and clarity of information given.

Acknowledgements

Support for this project was provided by the Maternal and Child Health Bureau, under Contract No. 00-MCHB-18A from the Emergency Medical Services for Children program, Health Resources and Services Administration, U.S. Department of Health and Human Services.

The National Association of Emergency Medical Technicians (NAEMT) gratefully acknowledges the contributions and support of the following individuals and organizations in the production of this document and the fact sheet *Family-Centered Prehospital Care: Partnering With Families to Improve Care*.

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