Family Centered Practice During Pediatric Death in an Out of Hospital Setting

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Abstract

Objective: To understand effective ways for EMS providers to interact with distressed family members during a field intervention involving a recent or impending out-of-hospital (OOH) pediatric death. **Methods:** Eight focus groups with 98 EMS providers were conducted in urban and rural settings between November 2013 and March 2014. Sixty-eight providers also completed a short questionnaire about a specific event including demographics. Seventy-eight percent of providers were males, 13% were either African American or Hispanic, and the average number of years in EMS was 16 years. They were asked how team members managed the family during the response to a dying child, what was most helpful for families whose child suddenly and unexpectedly was dead in the OOH setting, and what follow up efforts with the family were effective. **Results:** The professional response by the EMS team was critical to family coping and getting necessary support. There were several critical competencies identified to help the family cope including: (1) that EMS provide excellent and expeditious care with seamless coordination, (2) allowing family to witness the resuscitation including the attempts to save the child's life, and (3) providing ongoing communication. Whether the child is removed from the scene or not, keeping the family appraised of what is happening and why is critical. Exclusion of families from the process in cases of suspected child abuse is not warranted. Giving tangible forms of support by calling friends, family, and clergy, along with allowing the family time with the child after death, giving emotional support, and follow-up gestures all help families cope. **Conclusion:** The study revealed effective ways for EMS providers to interact with distressed family members during an OOH pediatric death

Key words: child; focus groups; death; resuscitation; Emergency Medical Services; family-centered care

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Introduction

There has been increased movement over the last fifteen years toward patient and family centered care (PFCC) in clinical medicine, especially among emergency physicians providing care to children.[1,2] This approach to practice places value in understanding the patient in the context of his or her family and culture and honoring that context, so as to lead to better health outcomes. Engaging in PFCC is not only important in the hospital but is also important in prehospital settings. The Emergency Medical Services (EMS) profession endorsed a 2006 joint policy statement between the American Academy of Pediatrics (AAP) and the American College of Emergency Physicians (ACEP) and a 2008 technical report that addressed PFCC in the emergency department and have acknowledged else-

where in the literature the important role that family members play at prehospital emergency scenes.[3–7] At the same time, it was recognized that EMS professionals have minimal training on how to effectively collaborate with family members, while also quickly attending to the pressing medical needs of patients.

There is a growing trend in favor of greater family witnessing of EMS interventions.[6] A recent randomized controlled trial compared those that did and did not witness CPR in adult relatives who subsequently died. It showed small but significantly lower levels of PTSD and anxiety three months later in those who witnessed the CPR compared to those who did not.[7] However, despite positive results of the use of PFCC in the literature, and policy statements endorsed by many health professionals, not all health professionals are in full agreement with all aspects of the recommendations. In fact, in the area of family presence during pediatric resuscitation, up to one third of health professionals (including nurses and physicians) are unlikely to give families a choice in whether or not to witness this intervention. Those who object to families witnessing the intervention often have concerns about the unintended emotional and legal consequences of so doing.[8,9] Those who are positive about family presence during pediatric resuscitation cite benefits of patients who feel supported, family members who feel positive about their own participation in the treatment of their child, and reassurance about what is happening in the situation, all of which tends to lead to fewer legal problems and healthier bereavement if a child dies. In light of the fact that not all hospitals or EMS services have policies in place that support PFCC, the standard of care may vary substantially, and even be unhelpful, depending on the provider on call in any given instance.

The pressure on EMS providers is always high but is especially heightened when a child is close to death or has died. This circumstance makes engaging in PFCC even more critical but also more difficult. The goal of the current study was to understand what actions were perceived to be the most helpful in assisting the family member in coping with such a huge loss. This question was addressed from the perspective of both EMS providers and family members who had experienced the sudden death of their child in an OOH setting or soon after. These findings, along with information gleaned from the literature, will be used to inform a family centered, evidence-based approach to the care of children who unexpectedly die in the OOH setting.

The intent was to interview a range of both male and female EMS personnel from diverse backgrounds who work in rural, suburban, and urban areas. By design, these providers have different educational or certification levels [Emergency Medical Technician (EMT)/Paramedic/Registered nurse (RN)/respiratory therapist (RT)] in both professional and volunteer positions in order to understand best practices for helping families cope with an OOH pediatric death.

Method

Data Safety and Monitoring Plan for Human Subjects

Activities involving human participants were approved by the University of Louisville IRB in August 2013 and by Norton Hospital in September 2013. All human participants completed a consent form.

Recruitment of EMS Providers for Study Groups

EMS providers were recruited from the Commonwealth of Kentucky (KY) and received a letter from the KY Board of EMS (KBEMS) executive director and Emergency Medical Services for Children (EMSC) Program Director and Manager, explaining the purpose of the study, the purpose and details of study groups (SG) and introducing the investigative team. Potential participation dates and times, stratified by location, were offered. The letter provided contact information for the SG coordinator, and interested personnel were encouraged to participate. A maximum of two follow-up letters were sent to enable sufficient enrollment of subjects.[10] All participants received a list of community resources and brochures to assist them in self-care activities to alleviate job stress. Opt out options were also offered.

The Commonwealth of KY is a primarily rural state located in the East Central United States (U.S.). It is often viewed, geographically and culturally, as both a Southern state and a Midwestern state. KY is the 37th largest state in terms of land area, encompassing 39,486.34 square miles, and ranks 26th in population in the U.S. The population density is 109.9 people per square mile. According to the 2010 U.S. Census Data, KY has a population of 4,339,397, including 8.0% Black, 3.2% Hispanic members, 1.2% Asian, and 3.1% foreign-born members. Median household income in 2006–2010 was $41,576 (compared to $51,914 in the U.S. as a whole) with 17.7% (U.S. 13.8%) living below the poverty line. Eighty-one percent of persons age 25+ were high school (HS) graduates in 2006–2010 compared with 85% nationally, with only 20.3% of individuals aged 25+ earning bachelor's degrees or higher compared to 27.9% nationally. Children less than 5 years of age account for 6.4% (U.S. 6.5%) of the population with the total number of children less than 18 accounting for 23.4% (U.S. 23.7%) of the population. According to The Appalachian Regional Commission, 54 of KY's 120 counties are considered to be in Appalachia. The underserved nature of this eastern KY area, relating to geographic isolation, financial,

cultural, linguistic, and workforce barriers that limit access to care, is well documented.

KY EMS System

The EMS focus groups (FG) were conducted in KY by trained facilitators. All facilitators were trained in focus group methodology in their programs of study and routinely conduct focus groups as part of their research and clinical positions. For this project, the facilitators worked together to develop the questions and protocols. The KBEMS has regulatory authority over the EMS System and personnel. At the time that the focus groups were held, there were 222 total EMS services. Of these, 38 were classified as basic life support (BLS) and 184 as advanced life support (ALS). Excluding air, non-transporting, and industrial services, there were 191 EMS agencies providing response and ground transport located throughout the Commonwealth. There were 9 aeromedical agencies licensed in KY with approximately 75 helicopters serving the Commonwealth. KY was in the implementation phase of data collection and reporting to National Emergency Medical Systems Information System (NEMSIS).

Medical Direction for EMS agencies is provided on a local level as each agency has its own medical director. Statewide pediatric protocols have been made available, with most agencies adopting them, in order to ensure consistent and evidence-based care. KY EMS personnel have been certified at the First Responder, Emergency Medical Technician (EMT), and EMT-Paramedic level. As of July 27, 2012 there were 697 First Responders, 9,573 BLS, and 2,897 ALS providers in KY. KY is undergoing a regulation revision that will change the title of certification levels to be compatible with the National Scope of Practice Model and introduce the Advanced EMT (previously Intermediate) level to KY. Moving forward, EMS personnel will be certified at the Emergency Medical Responder (EMR), Emergency Medical Technician (EMT), Advanced Emergency Medical Technician (AEMT), and Paramedic (P) levels. Recruitment of FG participants was achieved by obtaining a list from the KY EMS Director and EMSC Coordinator that included contact information.

Study Groups

Four study authors conducted eight regional focus groups of EMS providers in six different urban and rural cities in Northern, Eastern, Central and Western Kentucky (e.g., Louisville, Lexington, Madisonville, Elizabethtown, Pleasure Ridge Park, and Florence) between November, 2013 and March, 2014. Most focus groups included between 5 and 11 participants. One group had 26 participants who were available while attending an EMS conference. After the first focus group, the team decided to give all focus group participants a short questionnaire in order to help them remember an incident when a child died in an OOH setting and to gather key demographics more efficiently. This transformed the focus groups into study groups (SGs) since they both completed surveys and participated in the focus group methodologies. For seven of the focus groups, participants signed in, received study instructions and signed the consent form, completed the short questionnaire and then participated in a one to one and a half hour focus group. The entire exercise generally took two hours. For the first focus group, all of the same steps were followed, but the questionnaire was not included.

Questions Asked

A written interview guide was utilized to minimize deviation across groups. Facilitators ensured that all group members participated. At the conclusion of the first FG, participants were asked for feedback on the clarity of the questions and for suggestions about what else should have been included. Minor interview guide modifications were made based on this feedback, but none of the changes substantially changed the nature of the questions; therefore, the first FG is included in analyses. This paper focuses on questions aimed at helping family members cope with the situation (see Table 1 for questions directed to each group).[11]

TABLE 1. Questions Included in EMS Survey and Focus Groups

- Describe the most memorable pediatric arrest scenario you participated in as a direct provider, focusing on the family's reaction.
- How did you or members of your team manage the family during the response to the child?
- How did you or members of your team manage the family's response to the death or impending death of their child?
- What was most helpful for families whose child suddenly and unexpectedly was dead in the OOH setting?
- If you could replay the scene, how would you change what you did, if anything?
- What follow up efforts did you make with the family, if any?
- What kind of follow up do you think is appropriate for EMS personnel to undertake?
- How did you and your team cope after the run was complete? What did you do to care for yourself after the experience of the pediatric arrest?*
- What do you find helps in coping with this type of situation?*
- If there were training on managing family grief and coping with pediatric death*, what should be included in the training?
- If there were a tool focused on managing a pediatric death situation, with a focus on managing the family and coping with the event*, what should be included? How could such a tool be utilized?

*The response to these questions is included in another paper Barbee et al. [12]

Method for Analysis of Qualitative Data

Qualitative data were validated through a process of triangulation, using different methods, data sources, investigators, and theories to guide the interpretation of the data. The first coder combined answers to each question from across all of the written questionnaires.[11,12] Then, similar sentiments were grouped. Sentiments that had high overlap were combined. Next, each grouping was given a name that characterized the theme present in the answer. A summary of findings across all themes for each question was written. Answers to each question were then combined from across all of the focus group transcripts and audiotapes.

As with the questionnaire data, similar sentiments that surfaced during focus group discussions were grouped and sentiments that had high overlap were combined. Then, each grouping was given a name that characterized the theme present in the answer. Answers from the questionnaire and focus group methods were compared and combined. In cases where additional themes were present in either the questionnaire or FG data, all themes were retained in the final description. Any time specific suggestions were offered for intervening on the scene, helping families cope, helping EMS providers cope or helping co-workers cope with OOH pediatric deaths, these were gleaned and added to a list of potentially helpful strategies that could be included in the app, face to face training or other resource materials for EMS providers and families.

For inter-rater reliability, a second coder examined 10% of the questionnaire responses and focus group sentiments to verify groupings and theme extraction. Then, the second coder examined the final themes for each question and the list of suggestions to verify groupings and names of themes. Cohen's Kappa was .93. Results were shared with other members of the team who had observed many of the focus groups for further confirmation of the face validity of answers. Finally, results were shared with some of the focus group members to also verify the face validity of the answers.

Results

Study Group Participant Demographics

Ninety-eight EMS providers from urban, suburban, rural, and mixed settings across the state of Kentucky participated in the SGs. Most ($N = 68$) of those participants also completed the questionnaire and all provided information about their a) years of experience in EMS, b) type of training, c) type of position held, and d) exposure to dying children in OOH settings. It is noteworthy that 93% of study participants had been exposed to one or more pediatric deaths (see Table 2 for Demographics).

TABLE 2. Demographics of Focus Group Participants

Variable	Categories of Results	Number/Percentage
Gender	Male	76 78%
	Female	22 22%
Race	Caucasian	85 87%
	African American	6 6%
	Hispanic	8 7%
Years of experience in EMS	Less than a year	1 1%
	1–5 years	13 14%
	6–10 years	17 19%
	11–15 years	19 21%
	16–20 years	16 18%
	21–25 years	16 18%
	26–30 years	3 3%
	31–39 years	5 6%
Training	Paramedics	69 52%
	EMT	36 27%
	Firefighting	22 17%
	Nursing School	3 2%
	Police Academy	2 1%
	Other First Responder	1 < 1%
Current Positions in EMS	Administrator	26 25%
	Supervisors	10 10%
	Frontline	60 59%
	Special	6 6%
Setting	Urban	32 33%
	Suburban	16 16%
	Rural	33 34%
	All types of settings	17 17%
Exposure to OOH Pediatric Deaths	0 Deaths	5 7%
	1 Death	7 10%
	2 Deaths	7 10%
	3 Deaths	4 6%
	4 Deaths	7 1%
	5 Deaths	8 12%
	6 Deaths	5 7%
	7 Deaths	7 1%
	8 Deaths	7 1%
	10 Deaths	6 9%
	15 Deaths	3 4%
	20–25 Deaths	7 10%
	30 Deaths	2 3%
	75 Deaths	7 1%
	100–150 Deaths	2 3%
	A lot	7 10%

At the start of the focus groups, many stories of pediatric death in the field were relayed and addressed in order to give context to the answers. Sad and sometimes horrible deaths were described. These incidents were etched into the minds of the EMS providers. After describing incidences of pediatric death, EMS providers responded to questions about these events (see Table 3 for a summary of questions, themes, and exemplary quotes).

Seven themes were extracted from the answers to the question, "*How did you or members of your team manage the family during the response to the child?*" Initially, an EMS professional interacts with the family to gather facts about the situation, the child's demographic information, any pre-existing medical

TABLE 3. EMS Focus Group Questions, Themes and Exemplary Quotes

Questions	Themes	Exemplary Quotes
How did you or members of your team manage the family during the response to the child?	**Gather facts**: traditional AMPLE* history	*"Got as much info as possible as to times and actions they took."*
	Conduct medical procedures on child	*"While I asked questions, my partner was giving CPR to the child."*
	Decision about transporting child: A decision is made to "scoop and run" or "work the scene".	*"We scooped the child out of the mother's arms and ran to the ambulance and drove to the children's hospital."*
	Decision about whether to allow family observations	*"Family was moved to a second room."* *"Allowed family to watch until they started getting in the way of patient care."* *"We allow them to observe at a distance, but we do not tolerate interference."*
	Describe interventions to family regardless of whether working on the child or standing with the family	*"It is always helpful to have extra hands to manage the patient for a few moments while talking to the family. My partner and I always explain to family what we are doing."*
	Tangible support: Give support to the family in the form of aid, advice, actions, or objects.	*"Gave the mother a drink of water. Offered to call family or friends."*
	Emotional support: Provide emotional support to the family including assurances, condolences	*"We will do everything we can do to help your child."* *"Kept the family calm and transported the mother to the ER with the child."*
	Decision to allow family in ambulance	*"My partner explained to the Dad, who rode in the ambulance, what we were doing."*
How did you or members of your team manage the family's response to the death or impending death of their child?	**Explained actions**: Reiterated what they observed about child's health and what they did in response; explained why we stopped treatment.	*"Allowed family to witness resuscitation while explaining the event."* *"Try to communicate what is going on and answer all of their questions."* *"Explained why efforts were withheld or stopped. I don't like giving false hope."*
	Tangible support: Team members took actions to help the family cope.	*"Called their church or our chaplain."* *"Offered them tissues or water."* *"Let the parents hold the child."* *"Asked if there was anyone I could call for her."*
	Emotional support: Team members gave comfort, sat with family and expressed sorrow about their loss.	*"I am so sorry for your loss."* *"I spoke softly."* *"I gave them social support."* *"I sat with the mother for over an hour."* *"I hugged the family and gave condolences."*
	Allow family to vent: Even if the family was angry, took time to listen and answer questions.	*"Very awkward. Searching for words to try to make the situation better. Often families want to blame you or yell at you. I just take it."* *"Let them cry."* *"Listen- Mom had already accepted it. We listened to her as she expressed all of her emotions."*
What was the most helpful for families whose child suddenly and unexpectedly was dead in the OOH setting?	**Manage the situation professionally**: Be calm, coordinated and competent in the execution of duties.	*"The team trying to save their child."* *"Our team being mixed flowed fluently in response and controlling the scene. . . the divide and conquer method."* *"Response time, focus."* *"Treated child with compassion and care."*
	Remove child or family vs let them watch: Some providers thought it was better to move the child from the parents and others allowed watching **Give explanations about procedures**: Whether family watches procedures or not, they need to know what is going on.	*"Better able to assess and manage the patient when took away from area."* *"Get the child out of the chaos."* *"Allowing them to witness all that could be done for the child, the actual act of watching the EMS providers try their best seemed to help them make that transition."* *"Involved parent. Explained pre-hospital capabilities and competency."* *"Knowing we were there to help. Communication on what we were going to do and why. Us being honest when answering questions."*

(Continued on the next page)

TABLE 3. EMS Focus Group Questions, Themes and Exemplary Quotes *(Continued)*

Questions	Themes	Exemplary Quotes
	Tangible support	*"Allowing them to spend time with the child after the call was over."*
		"Having the Fire Department chaplain on site."
	Emotional support; allow family to vent	*"Having family members there to provide support to the parents/siblings."*
		"Just being there for the family- they feel like someone cares-actually cares that the tragedy has just happened. . . someone to talk to."
		"Just listening as the Mom expressed her feelings."
If you could replay the scene, how would you change what you did, if anything?	**Don't give false hope**: Be honest in words and deeds (don't do CPR on a dead child).	*"Really we give people a lot of false hope by working these patients like we do. No one wants to be the one to tell the family so we transport to the hospital and put it on the doctor."*
		"Should have been better prepared."
		I would have appreciated being able to task someone to exclusively care for the mother, so I could focus only on the baby."
	Not managing chaos well: It is best if there is a provider that can manage the family exclusively while others work on the child.	*"Wouldn't have been so dismissive of the stepmother who didn't know the child well."*
	Lack of professionalism or coping by EMS personnel: Because providers don't know what to say they sometimes say the wrong thing or leave the scene prematurely.	*"I would have liked to have been better prepared for the emotional aspect of the run at that time." I knew driving to the scene I would suffer after the run but had no idea the emotions I would experience while on the run."*
		"To not just inform the family but to include them in the process and help them understand the process and care given to their child."
		"More eye to eye contact."
	Enhanced communication with the family	*"Keep the primary caregivers close and more involved and informed."*
		"Allow family to observe intervention, tell the family more about efforts, try to help the family more."
What follow up efforts did you make with the family, if any?	**No follow up attempts made, allowed or desired**	*"Our policy does not allow follow up."*
		"I believe I do my job well and try not to get attached."
	Grieved with or offered sympathy to the family	*"Try to visit at ER or hospital if child survived time after cardiac arrest."*
		"I followed up with them immediately after the run in the counseling room of the ED. I hugged them and made sure they knew that we had done all we could do."
		"Attended visitation and funeral services."
	Checked in to offer help or connect to services	*"Followed up with the family; informed of grief counseling services."*
		"Assisted with contacting coroner and funeral home. Remained with mother at the hospital until additional family arrived.
What kind of follow up do you think is appropriate for EMS personnel to undertake?	**No follow up should be attempted, made or allowed**	*"We normally do not follow up after an event is completed."*
		"We worry the family is looking for someone to blame."
	There should be follow up referral to professional care as part of continuum of care	*"Leave it up to the family to initiate contact."*
		"We should be a critical starting point for the grieving process (make contact within 24 hours to make sure ok and to make referral)."
		"Referral to grief counselor."
		"EMS should have social services or therapist on staff to conduct follow up."
	Access to family to show EMS cares and to help EMS providers cope	*"If there is a standard of care, it ought to include follow up with every patient. It is what community medicine is moving towards."*
		"I think it is good for families to know that we DO care. . .. we want to know that the families are making it through okay."
		"We should at least send a card or flowers to the funeral home from the local EMS office that provided services."
		"We should follow up by phone or a visit. . . offer condolences."
		"We should be contacted about what was found during an autopsy. We need closure too!"

*Allergies, Medications, Past illnesses, Last oral intake, Events leading up to illness/injury.

conditions, and allergies to medications. Simultaneously, at least one EMS provider evaluates and conducts medical procedures on the child. A decision is made to either transport the child to the hospital or continue to work on the child at the scene. Sometimes family members are allowed to watch the procedures and sometimes they are not. In both cases, another EMS worker is usually talking to the family about the child's treatment. "*It is always helpful to have extra hands to manage the patient for a few*

moments while talking to the family. My partner and I always explain to family what we are doing. We allow them to observe at a distance, but we do not tolerate interference." The final three themes involved giving tangible support to the family, providing emotional support to the family and allowing a family member to ride in the ambulance with the child on the way to the hospital. The most common assurance offered was: "*We will do everything we can do to help your child*."

Among the 98 KY EMS professionals who participated in this study, there was overwhelming consensus to both allow the family to watch the proceedings and to have someone assigned to the family to explain what is going on, including to explain why certain procedures are utilized and to provide a calming presence, comfort and information. They believed this strategy is helpful so that the family sees that EMS professionals are doing all they can to save their child, and so that they understand, through visual cues and verbal explanations, what is happening to their child. EMS providers found that these activities calm most families. The decision of whether to remove the child or allow parents to watch treatment, however, is dependent upon several factors:

a) *Family reaction*: If family member behavior is overly emotional, loud, and uncontrolled or interferes with treatment then separation may be best. If family members are calm and controlled, they are more likely to be allowed to watch procedures from the side, either in the house or in the ambulance.
b) *Necessary procedures*: There was a belief among EMS professionals that it might be best to separate family when more invasive measures were needed because of the gruesome or distressing nature of some procedures.
c) *Staffing*: The fewer the number of professionals on site, the more difficult it is to manage the family. Thus, even when EMS professionals would prefer to include the family in treatment, they sometimes are unable to do so, due to understaffing. The first priority is to take care of the patient, that is, physical needs of the child in medical distress.
d) *Circumstances*: An important variable that affects the decision of whether or not to include family are the attributions made by the EMS professionals as to why the child is dying. Professionals tend to say less if they think a parent has abused, neglected, or unintentionally rolled over onto a child during sleep and suffocated the child. Some of this lack of communication is due to anger (trying to control it and be professional), or not knowing what is appropriate to say in these situations. Sometimes EMS interaction is minimized because of the presence of police.
e) *Number of injured or ill patients*: EMS workers noted that on some scenes there are multiple casualties. Sometimes the whole family is injured, so everyone is being treated. In major tragedies, everyone in the family is dead, so involvement of family in treatment is a moot issue.

Another key finding focused on level of honesty with the family regarding a child's prognosis. EMS providers disagree about how honest to be with the family. More fell on the side of honesty ("*If the child is obviously dead, we use the term dead*") rather than the use of euphemisms. However, most try to conduct some sort of intervention, even if they know the child is dead or dying. They believe that this allows the parents to see that every effort is made to save their child. Finally, some EMS workers reported not knowing the best way to handle the family and noted the lack of guidance (protocols).

When asked "*How did you or members of your team manage the family's response to the death or impending death of their child?*" most EMS providers gave examples of proper care through 1) providing reassurance, 2) telling what they were doing and why, and if they couldn't help, why not, 3) providing tangible support to the family, 4) providing emotional support to the family, and 5) allowing the family to vent. Some noted that they were curt or that they did not know what to say in this situation ("*We tried to comfort them, but we were unsure exactly what to say*"). Others noted that due to suspected abuse, they did not include family members in the process. Still others reported a reticence to interact with the family because of not liking them or the way they were behaving. Nevertheless, most families seemed to be helped in this terrible situation by EMS workers (a) giving tangible forms of support by calling friends, family, clergy, and chaplains; (b) allowing the family time with the child after the death, (c) giving emotional support, and an opportunity to vent and grieve.

Responses to the specific question "*What was most helpful for families whose child suddenly and unexpectedly was dead in the OOH setting?*" led to the following insights. Both the way the family reacted to the situation and the way the team enacted their professional duties were critical to family coping and getting the support they needed. There are strong beliefs by EMS providers regarding how a family should react. It is critical that EMS do a good job and that their coordination be seamless. Allowing family to witness EMS competency, attempts to save the child's life, and swiftness of action all help the family cope. Sometimes all of these efforts can be appreciated without the family actually watching the child undergo distressing procedures. Regardless, whether the child is removed

from the scene or not, keeping the family informed about what is going on and why is critical for family coping.

When asked "*If you could replay the scene, how would you change what you did, if anything?*" most EMS providers believed the situation was handled as well as possible given the tragic ending, although some mis-steps were recounted. Some providers were unable to control the scene and reduce chaos, whether the chaos was due to family hysteria or poor provider scene management. For example, "*One of my team members was very frustrated with the parent and that just made the situation worse. I should have removed that team member and put someone else in charge of talking to the family*." Still another regretted engaging in insensitive conversation. A young firefighter arrived on the scene where a son had committed suicide that morning. The firefighter said to the Dad "*How are you today?*" The Dad said, "*How the hell do you think I'm doing today? My son just hung himself!*" Some wished they had enhanced their communication with the family. "*I would have tried to answer the family's questions in more detail and been more persistent on getting help for the mother to care for the other children on the scene*."

The majority opinion was to not give false hope to parents. Research supports telling parents that, while the signs do not look good and the child appears to be in critical condition and may not make it (truth), that the EMS providers will do everything they can to try to revive or help the child survive (necessary hope).[13] The parents and siblings will have a lifetime to miss the child, but in that moment, they need to see that all efforts are being attempted. Otherwise they will always wonder if more had been done, could the outcome have been different (post-decisional regret). One EMS provider said, "*I would have worked the code inside, so that the family could see ALL efforts, instead of firefighters rushing the kid out*."

Providers were asked about any follow-up efforts that were made with the family. Most agencies did not allow, or discouraged, follow up by EMS personnel, although some have chaplains that are dispatched to help family cope after a child death. Some saw this lack of follow-up as a weakness in the system, although others thought it was appropriate. Some EMS providers make it a practice to stop by at the hospital or attend visitations or funerals. More than a quarter of respondents reported that they had checked in with the family to offer or give tangible support, to refer to other services, or to give ongoing emotional support. Others reported helping convict negligent or abusive caregivers of child abuse (non-accidental trauma [NAT]) in court.

The EMS professionals were asked what kind of follow-up they thought would be appropriate for EMS personnel. Few expressed support for no follow-up. Those that supported no follow-up either thought it was not part of the job or that families are looking for someone to blame. The latter EMS providers were not aware that showing empathy, offering connections to helpful grief and counseling services and sometimes even debriefing can provide great support for a family and make them less likely to blame the EMS team. Some EMS workers thought it was only appropriate to do follow-up if the patient survives. Others thought some providers need follow-up for their own coping, while others were better off not following up, which was dependent on the coping style of the responder. The types of follow up that were endorsed were referrals to professional care (e.g., a chaplain or social worker or other mental health professional) as part of a continuum of care. Others wanted the chance to offer condolences via a card, to call or visit, to debrief the incident or to receive information from the ED after survival or an autopsy if a death occurred. One EMS worker stated: "*I think it is good for families to know that we DO care. . . that we want to know that the families are making it through okay*."

Discussion

FG data are collected and influenced by the social milieu of peers, the same peers that may influence behavior in the field. While FGs cannot document the precise proportion of attitudes in a population, they can create a portrait of the range of opinions and concerns; this is achieved by conducting FGs until there is saturation of themes, indicating that the range (but not distribution) of opinions and concerns has been captured.[13] FG methodology attempts to elicit as many points of view as possible, ensuring that the programs developed on the basis of these data will meet the needs of a diverse population.

Many of the responses reflect movement towards patient and family centered care (PFCC) over the last 15 years.[14] Often, more experienced EMS providers noted that when they began EMS work 20, 30 or almost 40 years ago, there was no emphasis on helping the family cope with a crisis situation. Incorporating these new approaches to practice has been found to enhance the care that seasoned EMS providers gave to patients and families.[15–17]

A 2006 joint policy statement between the AAP and ACEP sought to address particular challenges in providing PFCC in emergency departments (ED).[3] These challenges included overcrowding and acuity, lack of a previous relationship between the patient/family and health care providers, cultural variations among families, visits related to abuse or violence, the need for time-sensitive invasive procedures, including resuscitation efforts, and the unanticipated death of a child. In light of these challenges and opportunities to align with previous policies, seven recommendations were made in the 2006 policy statement. The

TABLE 4. Recommendations for Providing Patient and Family Centered Care

RECOMMENDATIONS FOR PROVIDING PFFC IN EMERGENCY DEPARTMENTS*	RECOMMENDATIONS FOR PROVIDING PFFC IN THE FIELD†
1. Knowledge of the patient's experience and perspective is essential to practice culturally effective care that promotes patient dignity, comfort and autonomy.	1. Engaging the family members in order to understand not only the child's developmental stage and health status, but also the family's views on care based on their religion and culture.
2. The patient and family are key decision makers regarding the patient's medical care.	2. Assigning a professional to explain procedures to the family as they observe the scene or as they help keep the child calm during treatment.
3. The interdependence of child and parent, patient and family wishes for privacy, and the evolving independence of the pediatric patient should be respected.	3. Offering to give the family tangible support like calling clergy, neighbors or other family members, getting a parched parent a glass of water or explaining next steps.
4. The option of family member presence should be encouraged for all aspects of ED care.	4. Giving emotional support and comfort to the family members to help them keep calm during their child's treatment or after they have passed away. These offers of support were in the form of reassurance that they would or did do all they could to save their child, giving condolences after a child's passing, and expressing sorrow for the situation.
5. Information should be provided to the family during interventions regardless of the family's decision to be present or not.	5. Giving the family members the option to observe treatment; allowing a family member to ride with the child in the ambulance to the hospital and/or allowing family members to be with the child after death.
6. PFCC encourages collaboration with other health care professionals along the continuum of care and acknowledgement of the importance of the patient's medical home to the patient's continued well-being.	6. Being honest with the family about a child's prognosis or status ("*If the child is obviously dead, we use the term dead.*").
7. Institutional policies should be developed for provision of PFCC through environmental design, practice, and staffing in collaboration with patients and families.	7. Following up with the family after the event with a referral to a mental health professional or sending out a chaplain to the family home to give comfort or information about the grieving process, visiting the funeral home, attending the funeral, supplying autopsy results, sending condolences

*Mace and Brown, 2006.[3] †Recommendations developed from the current study.

recommendations extracted from the results of the current study mirror these seven official recommendations (Table 4). This AAP/ACEP report was expanded in a 2008 paper with further examples of how to enhance PFCC in the ED at each stage of patient entry and exit, although many are not applicable to the prehospital setting.[4]

Some responses by focus group participants showed less awareness of PFCC. No one mentioned asking family members if they wanted to watch procedures after explaining them. EMS professionals typically choose for the family whether or not to allow total, partial or no involvement with the care of the child. In situations where time is of the essence, EMS personnel must take control of the situation. Although the PFCC guidelines explicitly encourage family member presence for all aspects of care, including riding in the ambulance to the hospital, family members may be difficult, intrusive and so disruptive that EMS providers are prevented from doing their jobs. In those cases, if the EMS team cannot help the family calm down, it may be legitimate to exclude the family from treatment or transport. In addition, several providers noted that their organizations discouraged involvement of family members and follow up efforts. Finally, sometimes EMS providers recounted instances of negative interactions (e.g., adding to or failing to control a chaotic situation, being irritable with family members, engaging in seemingly benign, but often painful chit-chat with parents). Such behavior may be an expression of frustration but should be discouraged and remediated with education. There is still much to be done in revising policies to facilitate the provision of PFCC practices.

In a recent study, researchers interviewed 10 EMS professionals about balancing the needs of family members and patients who die in the field. The pressures exerted by family members to keep trying to revive a patient who is likely to already be dead or who is surely dying showed a need for an ethical and caring ability by providers to care for bereaved family members as well as additional training for EMS providers to care for themselves.[18] Thus, there is a need for training and other tools to help EMS providers move along the continuum of PFCC to reach high levels of competence.

In recent years, there has been a movement calling for or incorporating more realistic simulations into training that concern the care of pediatric patients in OOH settings[19,20] One study reported positive evaluations for training to teach EMS providers about family-witnessed resuscitation and death notification.[21]A second study found enhanced confidence and competency after EMS staff were trained in the GRIEV_ING method, using trained standardized survivors to improve EMS communication skills when working with grieving family members.[22] Another professional group called for EMS providers to grapple with ethical dilemmas common in their field, in order to sharpen ethical reasoning and enhance ethical practice with patients, including situations involving child abuse.[18]

Study Limitations

The 98 EMS providers who contributed to this study represented a cross-section of urban, suburban, rural and mixed settings. They all came from Kentucky, so replication of these procedures in other states, and in other parts of the world, is warranted.

The qualitative approach was appropriate for an area with little previous research. Future research, however, should build on these observations using quantitative survey methodology in order to reach a wider and more representative sample of EMS providers. Subsequent research may validate, expand upon, or refute specific observations made in this study.

Conclusion

This study elicited many examples of helpful behaviors that EMS personnel can employ when on the scene during a pediatric OOH death. These recommendations were generated by EMS personnel from their vast experience dealing with these types of situations. Although many insights mirror recommendations made by the AAP and ACEP to create more PFCC in EDs, they go beyond these recommendations with very specific gestures that can help families heal from such a traumatizing event. These findings and information gleaned from the literature will be used to inform a family centered, evidence-based approach to the care of children who unexpectedly die in the OOH setting.[23] This topic is unfortunately overlooked when highlighting inadequacies in pediatric prehospital education.[24] It is our hope that the insights gleaned from this study will be integrated into educational and training programs aimed at EMS providers and other health professionals who are likely to encounter the death of a child during their careers so that all families are consistently treated with dignity and respect during one of the worst days of their lives.

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