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Charting the Future of Out-of-Hospital Care

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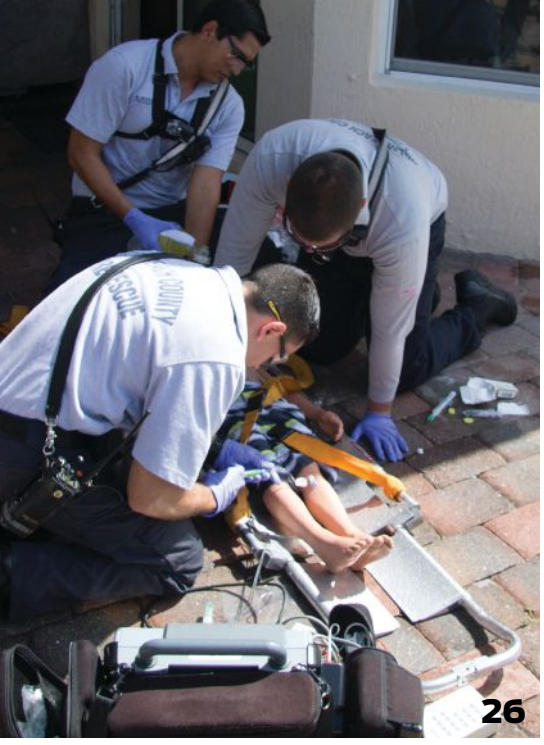

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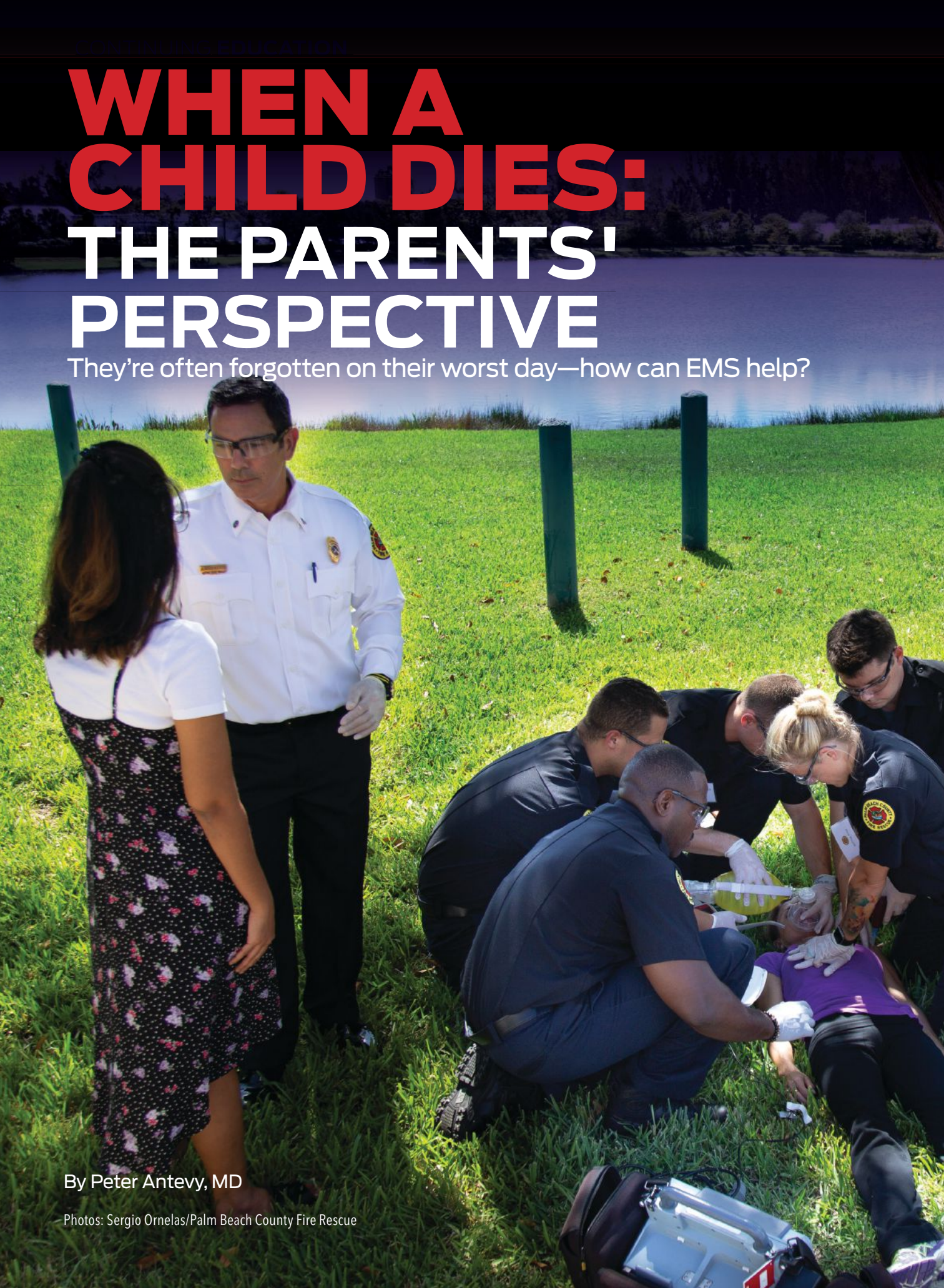

By Peter Antevy, MD

Photos: Sergio Ornelas/Palm Beach County Fire Rescue

A 6-year-old boy was playing in the street in front of his house when his father hurriedly put the car in reverse and accidentally ran him over. The scene was awful in every sense, mostly because the child suffered a head injury incompatible with life. The rescue and engine arrived and immediately focused on treating the child, yet quickly recognized the severity of the skull injury and that further care would be futile.

The father watched in horror. He stood there alone, screaming and crying, but what he needed most he did not receive: The crews that arrived on scene were prepared to treat the child but did not have the skill set to speak to the dad.

At that moment an EMS captain arrived, assessed the situation, and then did something that is not only difficult for most but rarely done at all: He turned and walked directly to the father and had the most difficult conversation he'd ever had. It was one both men would never forget.

Ask a paramedic, nurse, or doctor about their experiences with the death of a child, and you will see a clear and unmistakable change in comfort level and body language. No one wants to think about it, let alone talk about it—by distancing themselves from the emotions, they hope to be protected from the emotional trauma. Even though the before, during, and after phases of the event provide ample time for healthcare professionals to reach out and help bring the family closer, the choice is counterintuitive for most.

A newly published qualitative study in *Pediatric Critical Care Medicine* sheds an important light on this complex topic and brings great clarity to what parents truly need when their child is dying.[1] While the study related to children who died in a pediatric intensive care unit (PICU), the results are applicable across the healthcare continuum and inclusive of all specialties that care for children, including EMS.

The paper describes three key time periods related to pediatric death. Using direct interview questions, it elicits what parents want during this difficult process. We'll review the hospital side and then discuss how the EMS profession can learn from this important study.

During Hospitalization

In the study parents emphasized the need for honesty and wanted to be clearly and directly told their child's chance for survival was limited, as early as possible and with little ambiguity. Interestingly, they asked that information relayed by the medical team be written, drawn out as diagrams, and repeated multiple times.

Parents also expressed the need for a "respite room" that included snacks, toiletries, facilities for showering or washing clothes, and phone-charging access. The provision of meals, overnight accommodations, and improvements to access and costs of parking were mentioned as well.

They felt access to the PICU was difficult and that during such a difficult time, larger rooms with more natural light were important. In retrospect they felt early referral to community-based support services (counselors, pastors, etc.) would have great value, as well as improved support and resources for the sick child's siblings.

During the Dying Phase

Parents preferred to be in a private room with natural light, large enough for other family members to visit and demedicalized as much as possible. They also strongly recommended staff members stay with them after their child died.

Some small but important examples were that someone stay to help wash their child, pack their belongings, and even walk them out to their cars—and on that final exit out of the hospital, going home forever without their child, to please waive the parking fee. Then they emphasized something most of us in healthcare never think about: "How do I visit my child in the morgue?" When they finally figure that out, there needs to be a designated visiting room so parents can spend alone time with their deceased child.

During Bereavement

Families that have been through a tragedy like this will tell you that what happens after they leave the hospital is incredibly difficult. The feelings of denial and anger collide with the feelings of being alone, with a silence more painful with each passing day.

Every parent interviewed for this study strongly recommended routine follow-up care be offered.

Every parent interviewed for this study strongly recommended routine follow-up care be offered. Parents wanted more information on "what happens next"—things like what to do when they get home, how to plan for a funeral, and will there be a postmortem examination? How are they supposed to feel? Are there normal grief symptoms? The parents interviewed wanted to attend counseling or support groups and therefore needed a list of local bereavement services as they departed or on the follow-up call.

Parents were adamant that follow-up begin a few days after their child's death and taper off after one year. A phone call from someone who treated their child could give them comfort that their child had the best care possible and everything was done when it mattered most. They felt letters or, better yet, in-person meetings with those who cared for their child would be helpful in the healing process.

Another request that came up repeatedly was staff presence at funerals. This goes from EMS all the way through the hospital staff. And they stressed the importance of including the entire family in follow-up, including siblings and close relatives.

Another request was to be connected to parents of other families whose children had died. This could be accomplished via a hospital-based bereavement support group or parent buddy-system model.

Translating It to EMS

In EMS we encounter children during the dying phase, which puts us at a disadvantage. We must handle both the medical and familial aspects simultaneously. The opening example was difficult but managed extremely well by a seasoned EMS captain.

Take another example—pediatric drowning—during which the family is frantic, having suddenly been thrust into trying to revive their child, who was perfectly normal minutes earlier. When EMS arrives not only do families expect the highest-quality care, but they also need the connection and the "embrace" as their world goes into a tailspin.

Whose responsibility is this? Some may naively say, "I'm here to perform the correct medical procedures and transport the child to the hospital," but this isn't enough. The interviews from the study were very clear: Parents want a clear and direct explanation of what we're doing and why.

Resist the instinct to push the parents away or remove them from the scene when their ingrained parental response is to protect their child. Understand they have lost all control, and their feeling of guilt is overwhelming—avoiding or not acknowledging them may be the easier thing to do, but it's considerably off the mark.

Just like the EMS captain did on scene, at least one member of the team should make contact with the parent(s) immediately upon arrival to provide a rapid and clear explanation of the situation. Based on the situation, tell parents the truth: "Your child is in cardiac arrest, and we are doing everything we can to get him/her back to life before we start moving toward the hospital." It is important to emphasize that "we are doing exactly what the doctors would do at the hospital," and "we just need a few minutes to try to get your child's heart beating again so we can give him/her the best chance at survival."

Acknowledging the parent's emotional distress is perfectly acceptable. The person connecting with the family can say, "I know this is very stressful for you, and you may be wondering why we aren't rushing to the hospital." This gives the parent confidence that you recognize their concerns. It also acknowledges the elephant in the room, which for decades has resulted in children being scooped up and rushed to the hospital, often without critical lifesaving interventions.

In the nonarrest situation such as a seizure or AMS, it is helpful to point out the positive findings in simple terms. Here are some examples:

- "Come and hold your child's hand and feel that it's warm. That means he/she is getting good blood flow."
- "Notice how good the color is in his/her face. That's a good thing."
- "Come and look at the monitor. Notice how good his/her

By bringing the family closer, you give them more of a sense of control.

oxygen level is. The heart rate is normal, and his/her blood pressure is doing fine right now."

• "I want you to stay close by me if you have any questions. We are going to do a few more things right here before we go. I'll keep you updated."

These statements can be followed up with statements like these:

• "He/she isn't breathing so well on his own, so we will be assisting with that."

• "It appears he/she is in pain, so we will be giving some medications to make her feel better."

Finally, it is important to give some sense of control back to the parent. This can be done with a very simple question: "Is that OK?" When you tell a parent what you're doing, follow it up with "Is that OK?" This will create a bond between you and the parent that is invaluable. It will allow you to continue to provide the best care to their child while at the same time keeping your workspace unagitated by emotion.

By bringing the family closer, you will have given them back some sense of control. And if they say no, you will have to shift gears to better understand the source of their fear. Here are some examples:

• "Your child appears to be dehydrated, and we'd like to place an IV in his/her arm—is that OK?"

• "Johnny seems to be in a lot of pain, and I'd like to give him an appropriate dose of pain control using a nasal spray. Is that OK?"

• "Your child may have ingested a battery, and it's important that he get an x-ray, so I'd like to transport him to the children's hospital. Is that OK?"

En route to the hospital, if the family member is in the ambulance, give them ample warning that it will appear very hectic at the emergency department but you will find them to check in before you leave. Then don't forget to do exactly that.

This is what we teach as the first step to getting to closure. It's OK to approach the parent after you've transferred care to let them know the doctors and nurses are doing everything they can for their child. It's also OK to reiterate what you and your team did during the prehospital phase, as it reinforces that you indeed did everything possible to save their child's life. If you feel it's OK, use a personal touch (hold a hand or give them a hug, etc.) to convey your caring. Most parents need that embrace.

EMS and the Bereavement Phase

Does EMS have a responsibility after the death of the child, or should we assume the hospital will handle it? The study discussed in this article describes clearly that parents need and

BEREAVED PARENTS' RECOMMENDATIONS FOR END-OF-LIFE AND BEREAVEMENT CARE		
DURING HOSPITALIZATION	**DURING THE DYING PHASE**	**DURING BEREAVEMENT**
Information and communication · Clear early discussions of potential/likelihood of death; · Tacit permission to withdraw life support; · Provide verbal and written/pictorial information, including pictures and diagrams.	**Before death** · Provide a private room, demedicalized as much as possible; · Allocate familiar clinicians; · Offer professional photographs of the child.	**Follow-up care** · Staff should attend funeral; · Pay particular attention to anniversaries, holidays, special days, etc.
Providing resources · Provide a parent room with bathroom, snacks, Internet, phone charging, etc.; · Organize/assist with meals; · Improve parking; consider waiving or reducing cost.	**After death** · Provide information on morgue visitation; · Walk parents from the PICU to their car; · Assist with transport home.	**Information** · Provide a list of local funeral directors, counselors, and grief-support groups; · Provide a "what happens next" guideline.
Environment · Orient parent to hospital and local community services; · Make PICU entrance processes simpler; · Explain when asking parents to wait outside.		**Connection** · Organize a support group for bereaved parents; · Develop a "buddy system" for parents before a child dies.
Support · Connect parents to external support services as early as possible; · Provide a support worker for siblings.		

–Adapted from Butler AE, Copnell B, Hall H. When a Child Dies in the PICU: Practice Recommendations From a Qualitative Study of Bereaved Parents. *Pediatr Crit Care Med,* 2019 Sep; 20(9): e447–e451.

want follow-up. EMS should absolutely be part of that equation.

Every agency should create a process in which someone (preferably someone with experience) calls the family to offer condolences and bereavement support. It also sends a powerful message when an EMS representative attends the funeral. It tells everyone in attendance that this is a group of people who truly care, and they are not hiding from anything.

If this feels counterintuitive, that's OK. The findings presented above are counterintuitive too. Bereavement is not straightforward, and it requires a deep understanding of what parents are going through during their most difficult time.

The Palm Beach Experience

Over the past few years, Palm Beach County Fire Rescue (PBCFR) has trained on both the medical and emotional aspects of pediatric care in the field, with an additional focus on bereavement in the days and months following a death. Training on high-performance CPR goes hand in hand with training on how to speak to family members upon arrival, on the scene, en route to the hospital, and prior to departure. A social work team is also immediately notified of the incident and responsible for contacting the family to assist with bereavement.

We have also instituted a call with medical direction to review the medical aspects of the call and discuss who engaged the family and how that went. Through this process we have recognized the power of getting closure by having difficult conversations. These lessons have been invaluable on many levels.

Parents have been grateful for the

calls they've received from the PBCFR team and reported a sense of a "strong embrace" when we attended their child's funeral. This more holistic approach has made a big impact in the lives of many on both sides of the equation.

No one except those who have suffered the death of a child can ever understand the difficulty and horror of that experience. However, if we do the right thing, coming closer instead of running away, we will soften the blow and perhaps even save another life.

This is exactly what that EMS captain did by walking toward the distraught father when he could have easily just advised transport and avoided the difficult interaction. We can all learn from stories and research papers like this. Let's embrace others when they need us most, and perhaps one small gesture can change someone's life forever.

> **If we do the right thing, we can soften the blow and perhaps save another life.**

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