EMT testimony on ED and EMS protocols:

As a student performing clinical rotations in a rural ED, I had first-hand experience with the lack of proper patient care that can happen when prehospital and ED staff are not properly trained and educated in adrenal crisis. In NC, we have a small footnote in the Hypotension/Shock Protocols that instructs paramedics to give an IM of steroids in cases of Adrenal Insufficiency or suspected Adrenal Insufficiency. However, most EMTs have not yet been trained in the new footnote or what it means for AI patient care and I found, after polling almost 400 NC EMTs, that only a handful knew of the existence of this footnote.

While working as a student in a rural ED, a Paramedic and her EMT partner brought an AI patient in decompensated shock into the ED. They did everything right to manage a typical shock patient, had this patient not had AI: they started large bore IVs and administered boluses of normal saline, they gave dextrose for low blood sugar, they even tried external warming techniques because their patient had developed a low core body temperature. However, when they brought their patient into the ED, his blood pressure and blood sugar were not responding to their treatment and his core body temperature had fallen to a shocking low. As they gave a report to the staff gathered in the room, I heard the paramedic state that he had Addison's disease. I promptly asked the medic if she had given steroids. She told me that she had not and didn't know why she should. We discussed the footnote in the hypotension/shock protocol that instructs medics to administer steroids to patients in adrenal crisis. I explained to her that this was the reason her patient was not responding to traditional shock treatment and if she had done so, she would have reversed his shock within about twenty minutes. I then turned to the doctor and nurses in the room and announced "did you all hear that? He has Addison's disease and has not received steroids." The doctor responded "Addison's. I think I heard something about that back in med school." She and the nurses said that it sounded familiar, but they didn't know what it was.

I took this opportunity to explain AI and steroid administration. The doctor smiled tolerantly and left the room. Our patient did not get steroids. I explained AI to the primary nurse assigned to this patient and why he needed steroids. We expected the doctor to order hydrocortisone and, when she didn't, I changed tactics and asked to see the lab results on his ACTH and/or cortisol levels when they came back. They were never drawn. Despite my protests and attempts to teach, I was just a student and my knowledge was disregarded. Thankfully, after many hours of aggressive treatment of symptoms, the patient regained consciousness. When I spoke to him, he asked "Did I get my steroids?" I told him that he had not gotten steroids.

The patient did not know that he could carry his own injectable Solu-Cortef for emergencies and had never heard of it, stating that he usually has to go to the ED and get steroids there.

This patient had a good outcome, but so many don't. Thanks to this patient, NC now has protocols for adrenal crisis in development to get treatment out of the footnotes and into the hands of medics who can save patient's lives. I've begun training county agencies throughout NC on recognition and treatment of adrenal crisis in the pre-hospital setting and, in just a few months since beginning training, one county reported that they have had six patient contacts with adrenal insufficient patients. Two of those patients – one adult and one pediatric - required steroid administration.

A UNC ED resident did a clinical rotation on my ambulance. Never one to waste an opportunity to improve patient care, I talked to him about AI and adrenal crisis. Several weeks later, I saw this resident again and he told me that he had a patient in adrenal crisis come into the ED. He said that thanks to our conversation, he knew what it was right away and this patient had no delay in receiving life-saving steroids. Medical professionals who are educated about AI want to help our patients. Death from an adrenal crisis is a needless sorrow and it is our responsibility as patient advocates and as the first line of stabilizing treatment for these patients to see that they get the life-saving medications that they need.

Cheryl Kornegay NC EMT-I

When an EMT's Child Had and Adrenal Crisis

I am an EMT and the parent of a child with Adrenal Insufficiency. My state has state-wide protocol allowances to treat Adrenal Crisis in Adrenal Insufficient patients or in the suspicion of Adrenal Insufficiency with the administration of steroids. However, this allowance is buried in the footnotes of the hypotension/shock protocol and, after polling around 400 EMTs and paramedics in my state, I have found that very few are aware of the existence of this protocol allowance. I am personally organizing training throughout the state on Adrenal Insufficiency and current protocol allowances, however the training for the county in which I live is still several months away.

Recently, my son had an adrenal crisis that was caused by a combination of ear infection and bodily stress from two hours of tennis practice. We had just

arrived home from practice when the crisis happened. His blood sugar was too low to register a reading on our glucometer and my son began presenting with an aggressive, irrational altered mental status that made simply giving his shot extremely difficult. As I tried to prepare his emergency shot of Solu-Cortef, a multi-step process that is near-impossible to do one-handed while holding a struggling child, I thought hard about whether I should call 911 for help. I had one major reservation: the fear that the medic who arrived at my house would not treat my child.

I have a good reason to question whether my son would receive proper treatment. Recently, I discussed training on AI for the county in which I live with a colleague who works in my county of residence. As I spoke to this colleague, I made the mistake of beginning the conversation by mentioning that my child has this condition that I will be training them in. This colleague latched onto the idea that this is a "rare" condition and this clouded his ability to understand the fact that our state ALREADY has guidelines for treating adrenal crisis with steroids. The reality is that he should already know and be implementing treatment for adrenal crisis per protocols and a lack of training is the only reason that he is not aware of this. It was clear through the discussion that this paramedic did not understand that it's already in our protocols and stated that paramedics know standard shock treatment so well that they have no reason to memorize footnotes that deviate from standard treatment.

This colleague of mine then stated to me that there are "plenty of crazy parents who call EMS and want special treatment for their kids" and he's sorry that one child in his area (my son) could die if he doesn't administer steroids, but he has 1,000 other children in his area that don't have this condition and he'll save those. I told him that it's not just my son, I know of three pediatric patients in this response district with adrenal insufficiency. his reply? "That's three. There are 1,000 others I will save.' As though it's okay to let three children die because he can't be bothered to read the footnotes and complete one additional step. Three who he would let die because can't be bothered do the job that our state already asks us to do.

And so, as I held my struggling child and tried to decide whether I had the strength and dexterity to treat him myself or if I needed to call for help, I thought about that medic who works in my area. He was working that day and there was a chance he would respond. I wondered how long it would take for my child to get proper treatment if I had to argue with the medic that came to our house even if it was a different person. I wondered if I couldn't just try harder to stabilize him myself and get to the hospital faster if I didn't have to explain the condition and prove the existence of the footnote. I wondered if who ever came to my door when I called 911 would

even allow me to give my child the shot or if, because they didn't understand the medication or condition, they would prevent me from giving it to him as so many other parents have had happen. I wondered if they didn't let me give him his Solu-Cortef, would they still give him the Solu-Medrol that is in their protocols. And I wondered, I am almost ashamed to admit, that if it came to a battle of wills between me and the medics that responded, would that damage their willingness to take instruction from me when I formally train them in a few months. Would a negative encounter with them over the treatment of my child cause more delays in the treatment of other AI patients in my county?

So, I managed at home. I didn't call for the help I needed. I stabilized my child, with great effort, by giving him emergency hydrocortisone and then treating his blood sugar orally. Then, we drove to the ED in my own car, with my now treated and stable child, where I had a three hour wait before calling the hospital pediatric endocrinologist on-call from the ED waiting room.

I can't help but wonder what would have happened if I had not been home. What if my teenaged daughter had been babysitting her little brother when the crisis started? There's no way she could have treated him herself with him in that state. Would she, a young girl, have been able to stand up to Paramedics who refused to treat her brother because they don't know that hidden in a footnote, they already have permission to treat? Would they have listened to her if she had the courage to tell them what to do or if she challenged their dismissal of her knowledge of his medical needs and their protocols?

I like to think that the colleague who told me that he didn't think it was important to save three children in his district when he has 1,000 is a rare case. The vast majority of medics who I have encountered have integrity and are driven by the desire to help and serve their community and we have had overwhelmingly positive response to the need for training and protocol creation throughout the state. So much so that we now have new protocols for Adrenal Crisis underway. Yet, I was afraid that he, or someone else who didn't understand this hidden protocol, would respond to my own child. This one paramedic is a symptom of a greater problem that can sometimes exist in EMS: lack of clear treatment protocols, egos that can sometimes get in the way of patient care, and an unwillingness to accept parental authority on health conditions and treatments that they don't understand or haven't been trained in. This is why clear, separate protocols for Adrenal Crisis are so important. Medics cannot help, even if they very much want to, without clear permission to treat. They can't help without training. No parent should have to wonder if calling for help from the people who exist to give it will cause more harm to their child than good.

Cheryl Kornegay

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