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EDITORIAL

Role of parents in paediatric emergencies: Tradition, conflict or improvement? *



Papel de los padres en las urgencias pediátricas: ¿tradición, conflicto o mejoría?

J. González del Rey

División de Urgencias Pediátricas, Cincinnati Children's Hospital Medical Center, University of Cincinnati College of Medicine, Cincinnati, United States

Medicine, like science, is making great strides nowadays. New discoveries, access to information, early diagnosis of complex diseases and new modes of treatment are bringing changes of great benefit to patients visiting our health care centres. However, many patients, administrators and observers of the medical process take the view that we are a "scientific society" firmly entrenched in traditions which make it difficult to incorporate new discoveries into clinical practice quickly enough for patients to benefit from them. Others, including members of the health care team itself, cannot understand how we arrived at the model that is still current in many of our hospital systems.

Let us take the concept of *emergencies* as an example to explain why I use the word *tradition*. Using a simple definition, we could describe an emergency department as "the section of a hospital where patients with serious illnesses or injuries needing immediate medical care are treated". To put it briefly, it is the area where we assess patients who have experienced an unexpected event — regardless of its seriousness — that requires special attention and a rapid solution. Add to that the fact that emergency physicians do not know the patients they are treating and that diagnosis

E-mail address: javier.gonzalez@cchmc.org

can be difficult and can involve numerous specialties, not to mention the patient's level of anxiety and the inefficiencies of the system that impede the communication process. To complicate matters, let us now introduce the adjective paediatric, which makes the diagnostic challenge even more difficult, further impedes communication and triples the level of anxiety. Why, then, in 2014, do we still entrust these patients to resident medical interns (MIR) with very limited experience and no direct supervision, generalist physicians with no training in critical resuscitation procedures, difficult airway management and other basic concepts of emergency medicine? It seems inexplicable that the patients that pose the greatest diagnostic and procedural challenges should be treated by the doctors with the least training and experience. We feel the effects on a daily basis, but it was and is part of our "tradition". It is true that our colleagues in intensive care, anaesthesiology, orthopaedics and the other specialties are always ready to help in the management of these patients. But how many children have been discharged with an incorrect diagnosis, and how many have been managed less than optimally while that help was on its way, for lack of sufficient clinical experience to establish a diagnosis or skill to perform procedures? This "tradition" has proved very hard to change and progress is still slow. Medicine has existed for many years, and yet the first training programme in general emergency medicine in the United States was not approved until 1970, and only in the 1980s were the first training programmes in Paediatric Emergencies approved.

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J. González del Rey

Let us continue with our analysis of the title: "conflict: a state of struggle, disagreement, rivalry or opposition between people or things." This is the most difficult part to understand if we look at it from the point of view of the patient or the patient's family. The fact is that family members who visit our emergency departments do not do so to argue or create rivalry. They actually visit them because, regardless of who treats them, they are looking for help. I use the word *conflict* because the attitude sometimes taken towards the presence of family members in paediatric emergency departments is based on tradition, not evidence. How would we feel, as doctors, if our son or daughter needed the services of an emergency department and we were asked to leave him or her alone with strangers during the procedures? I am sure we would suffer inner conflict, since we would want them not only to call in someone with a lot of experience or training, but also to allow us to play a part in discussing treatment options and indeed to help comfort the child (and why not?). The conflict, from my point of view, is between tradition, which offers me a system, my experience in the medical system that shows me that I ought to be using other resources, and logic, which gives me no explanation of why, as a parent, I cannot be at my child's side, precisely when he or she most needs me.

Reading the first two paragraphs, one might assume that I am a pessimist, and even perhaps regard me as a detractor of our systems. Quite the opposite; these experiences and thoughts, based on our traditions and conflicts, lead us to reflect on the last word in my title: improvement. Tradition "invites" us to think that the health system is made up of doctors, nurses and technical staff who treat patients in the context of an emergency department, either independently or as a team. The conflict arises when we are familiar with this system and try to adapt it on the basis of traditions or personal needs. The improvement comes when we combine those experiences with new definitions of quality. In 1998 the Institute of Medicine in the United States published two reports: To Err is Human and Crossing the Quality Chasm. 1,2 These evidence-based reports challenged the system and defined quality in a provocative way. They included "Patient Centered Care" (or "Family Centered Care" in paediatrics) in their definition of the concept. As happens in any process of change, the medical profession initially reacted against this idea. "We have always concentrated on treating the patient"; "we always keep our patients informed": these reactions, and many other similar ones, were expressed. However, the challenge went beyond keeping patients informed or concentrating on their treatment. It meant that family members (or patients) had to participate in the discussion, assessing options, being active members of the team, and being present at the most important moments in their diagnosis and treatment, or those of their loved ones. It is a simple idea, but one that was very difficult to grasp, because traditions kept us tied to inefficient processes. Let me explain what I mean. Take the example of a child admitted with convulsions. Generally speaking, all drugs taken orally are administered by nurses. When the child is discharged, the families are given the prescriptions and the drugs themselves, which have to be administered by them at home. There is nothing wrong with this, but it could perhaps be seen as an unsafe and very inefficient process. Why do all the instructions that could have been discussed and practised during the 48 h of hospitalisation have to be summed up in 10 min during discharge? Would it not be easier to educate the family in the use, administration and calculations associated with the drugs during hospitalisation rather than waiting until those last few hasty minutes before leaving? As doctors, parents and members of a complex system, we have to begin to understand that the more levels of observation and communication there are, the safer clinical practice will be and the easier it will be for us to understand the importance of involving parents in emergency care.

Having set out these arguments, I am going to answer my initial question on the role of parents in paediatric emergencies not as a physician but as a parent and an observer of a systemic change in our hospital from 2001 onwards. As a parent, I now have the right to take part in the bedside rounds and medical discussions concerning my children. I am confident that my doctors will be up to date with the scientific evidence and will present me with the best diagnosis and treatment options, and that they will make important decisions on the management of my children. Being informed of the treatment plan introduces another level of safety and facilitates communication between primary care physicians, specialists and nurses. As a parent I have a right and a duty to accompany my child during procedures, especially if they are painful. By doing so I can help the medical team to calm my child and to explain to him or her in familiar language what they are going to do and why they have to do it. I understand that if I behave in a way that does not comply with the rules laid down by the team, I lose my right to participate. Like these initiatives for including families in the care of their children, there are many others that have been considered and have proved to contribute to safety, efficiency, satisfaction and improvement, from the point of view of the medical team and the families.

In our hospital, processes involving the participation of family members have been designed as part of our mission to improve quality. For example, bedside rounds include medical staff, nursing staff, resident interns (MIR) and relatives, resulting in increased efficiency, safety and work satisfaction.³ There are family members that take part in training residents in communication, professional relations and management of patients with chronic illnesses. In our emergency department the rule is that families are present at every stage of diagnosis and treatment and while procedures are performed, including cardiopulmonary resuscitations.⁴

Of course, all this was implemented not by imposing administrative regulations but through a change of working practices and culture. It has been a very long process, but at the same time a satisfactory one. It was achieved by gradually educating ourselves, working as a group, accepting suggestions from all members — including the families — and developing rules of equality and ethics that facilitated the transition from tradition and conflict to improvement.

To leave you with the challenge, let me conclude with a personal experience. During a shift in the emergency department we received a girl by air transport with multiple injuries, whom we were unfortunately unable to resuscitate despite almost 45 min of intense efforts. The parents were present and in direct communication with me and with the nursing staff throughout the whole resuscitation process.

They could see everything we were doing, and when the time came to make the decision not to continue, they took part in the decision, kissed their daughter on the forehead and said goodbye to her... and they thanked us for the fact that they were able to spend their last minutes with their daughter in the company of people who respected their rights and did everything possible to save her.

Finally, as a parent I have a right, a duty and a responsibility to participate, assist and contribute in all aspects of the care of my children, as an active member of the emergency medical team, so as to prevent certain traditions from making it more difficult for them to receive the highest quality of care, and to prevent the conflicts that exist in our systems from limiting the capacity for improvement that we as doctors can bring to paediatric emergency services.

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