

The Importance of Attending Patient Funerals

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In my career as a pediatrician, I have gone to many funerals. I have cared for 28 children with recessive dystrophic epidermolysis bullosa (RDEB) in both primary care and hospital inpatient settings and attended 12 of their funerals. These funerals celebrated lives that had meaning, that brought great joy as well as heartache to their friends and families, and that made the world a better, more tolerant and understanding place. At 2 funerals, almost everyone wore pink, the girls' favorite color. At another, almost everyone wore T-shirts with Batman, the boy's favorite superhero. At another, the church was a sea of Bronco orange because of the boy's football passion. At others, we learned about a boy's well-delivered comedy routines, a girl's love of horseback riding (her horse was outside greeting people as they came to the service), and a girl's love of making lasagna. Attending these funerals provided us with a valuable perspective on the lives of chronically ill children with a terminal illness. They also helped us cope with our frustration. Why could we not have done more to alleviate our patients' suffering and delay the deaths of these children? We gained a deeper understanding that these children, despite their terrible disease and suffering, brought enormous joy to their parents and friends. Our entire team had the satisfaction that our care and support helped to maximize life's joys for these patients and their families. The families were always grateful that we could be with them to say goodbye to their child. The advanced practice nurse on our team wrote me the following message: "While I would never want to be in their shoes, raising a child with [epidermolysis bullosa], to walk alongside them and try and make the load a little lighter is a privilege and an honor." Residents who care for terminally ill children and establish a positive relationship with the families of these children are likely to experience similar feelings and benefit from attending their patients' funerals. When faculty, nursing staff, and other involved health professionals attend patient funerals together, there is an opportunity for mutual support and sharing of unresolved feelings of inadequacy, failure, guilt, and anger. Two residents who helped care for children with RDEB went to those children's funerals with me. Parents recognized the residents and appreciated their coming, and both residents commented that coming to the funeral made them feel better about how they cared for the child and helped the family. Attending the funeral was a meaningful experience that they greatly appreciated. Residents who helped care for a patient who has died benefit most from this experience.

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Each of these funerals brought back memories of bonding with children and their families. There were home visits, going to birthday and holiday parties, attending Bronco football games and Nuggets basketball games together, riding the Winter Park ski train to attend our “Camp Spirit” winter camp for skiing and dog sledding, and attending high school graduations. Caring for children with RDEB went beyond providing traditional medical services. Gaining an appreciation for lives outside of the hospital helped to build relationships and trust, which improved our ability to provide the best possible care. In addition, we just had fun together at activities outside the hospital, which made coming to appointments a bit less stressful. We also wanted older patients to feel good about helping younger children cope with RDEB. They were invited to participate in a filming of an epidermolysis bullosa (EB) video for schools, which the Dystrophic Epidermolysis Bullosa Research Association still distributes worldwide. Providing the best care for children also required our EB team to take on organizations that had no knowledge of RDEB. We successfully advocated for patients with Medicaid (coverage for high-cost dressings, vitamin D supplementation, special types of iron supplements, scooters and wheel chairs, and visits to the EB clinic for out-of-state patients), the hospital (baths and dressing changes in the hospital and restrictions on leaving the room because of methicillin-resistant *Staphylococcus*

aureus), medical supply companies (inadequate dressings and failure to provide a sufficient number of gastronomy tubes), home care agencies (failure to provide nurses with help for dressing changes), airlines (refusal to allow patients to fly), and schools (refusal to have an individualized education program and provide a paraprofessional, refusal to handle mobility issues, and refusal to allow patients to attend school). We did our best in schools to lessen the stigma of this disease. Our key goal was always to improve the quality of life for children who had a diagnosis on paper that left little room for anything but suffering. We raised money to buy iPads, Internet service, home yoga teachers, walk-in bath tubs, air conditioners, and, when not covered by insurance, dressings, medications, and vitamins. When a patient’s condition deteriorated, the child transitioned to palliative care to have a respectful, peaceful, pain-free death surrounded by loved ones.

For several years, I have been meeting for lunch monthly with first-year pediatric residents during their advocacy rotation. During this lunch, the residents often ask me about how I became involved with caring for children with RDEB. Our discussions frequently transition to their concerns about becoming too emotionally involved with dying children and their families. They are not sure how they will cope when they must care for children who experience so much pain and suffering. Helping residents cope with these types of clinical situations

has been a long-term concern of mine because I experienced these difficulties during my residency.

Program leaders need to address the concerns of residents about their own abilities to become emotionally involved with their dying patients while providing the best possible medical care. Educational research in this area is limited and needs to become a higher priority. Participating in the care of our patients with RDEB and observing how a team like ours interacts with these patients and their families is 1 way to do this. Teaching about death and dying through a seminar is another way. Sharing stories and modeling how to support and care for patients and families outside of the hospital or clinic room is yet another way.

However, it is only recently that I have recognized that attending the funerals of our patients (and encouraging residents who helped care for these children to do so) is yet another way. I have gained a fuller appreciation of the rewards of helping parents and families navigate a shortened life course with every funeral that I have attended. I believe that residents will understand this as well and that these rewards are at the core of being a professionally satisfied pediatrician.

ABBREVIATIONS

EB: epidermolysis bullosa
RDEB: recessive dystrophic epidermolysis bullosa

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