PEDIATRICS PERSPECTIVES

The Impact of Gun Violence on Those Already Dying: Perspectives From a Palliative Care Physician

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The consult was for a 19-year-old man with Duchenne muscular dystrophy who was in the ICU with respiratory distress and weight loss. Given his degenerative disease, establishing care with the palliative care team made perfect sense. It was, by all means, an appropriate consult. As our team sat down at this young man's bedside, we were joined by his mother. The patient himself would gesture yes and no because speaking was difficult, so out of both fatigue and shyness, he deferred to his mother to answer for him.

We introduced ourselves and explained our role with patients and families in the hospital. We asked our usual opening question: "Tell us about your son."

What followed was not the story you would expect to hear, one that would focus on symptoms related to serious illness or questions about advanced care planning. This story was different. A soft-spoken woman explained how she had cared for her son for the past 19 years: a boy she described as loving sports, enjoying music and home cooked food, and smiling almost constantly. When we explored further to elicit her hopes and worries for her son, she described a hope that he would be safe. "Safe?" our team questioned, "Tell us more." She went on to share that the community in which they lived was an area of extreme violence. She told us that bullets had found their way into the living room and remained lodged in the wall, a constant reminder of the danger lurking outside. This mother knew that her son's illness was progressive and life-limiting. She knew his health would continue to deteriorate with time, and he now required significant support with his activities of daily living, such as eating and bathing, yet her fear was that a bullet would take his life before his complex illness did and she would lose the precious time she had left with her son to a situation of violence.

I am completing my fellowship in pediatric palliative care, and this is not the first time I have heard a story like this. Another patient, a 16-year-old boy with cardiomyopathy and poor heart function, was being evaluated for

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a heart transplant, requiring him to meet with specialists from all over the hospital. He heard about the risks of surgery, the complications from transplant (including infection and rejection), and the uncertainty of time it would take to potentially receive an organ. While exploring with this young man what his worries were about anticipating a transplant, he said that he feared he would die from a gunshot wound in his neighborhood while on the wait-list before a heart was available. He could not focus on the fear of being in the hospital or of a surgeon opening his chest. His mind, instead, had to focus on personal safety because he was at risk each day he walked through his community.

As a palliative care clinician, I am being trained to master communication in an effort to facilitate difficult discussions. Eliciting a patient's fears and worries is an inherent part of a palliative care consult. Perhaps this allows me to more easily identify concerns for violence in an already vulnerable population; or perhaps these patients and families recognize they are not immune to the risk of death given their current reality of a life with serious illness, bringing the fear of violence to the forefront of their minds. Any child who is faced with hospitalization experiences a loss of control over their environment, which may mimic the same sense of loss of control experienced by living in a community where violence is highly prevalent. It seems more likely, however, that this fear of gun violence permeates beyond palliative care patients or children who are hospitalized, especially in a city like my new home, where 880 people have already been shot this year.[1] The conversations I have had with children and families have emphasized that gun violence remains a fundamental threat to public health. And this issue is currently being recognized as a priority for all pediatricians by the American Academy of Pediatrics (AAP).

In 1992, the AAP released a policy statement titled "Firearm-Related Injuries Affecting the Pediatric Population" and revised this statement in 2012. By 2012, firearm-associated deaths among youth ages 15 to 19 years had fallen to 11.4 per 100 000 nationally.[2] Despite a national downward trend over nearly 20 years, in 2017, the firearm homicide rate among youth ages 15 to 19 years in my now hometown of Chicago was 20 per 100 000, a rate that has not changed in 15 years.[3] According to the Chicago Police Department, there was an average of 8 victims of gun violence per day in Chicago last year alone.[4] And although Illinois was 1 of 27 states in 2018 to pass new gun-control laws, including Senate Bill 337 (the Combating Illegal Gun Trafficking Act), 7 other states passed new gun-rights laws.[5]

At the AAP Legislative Conference in Washington, District of Columbia, this past April, >300 pediatricians from across the country lobbied for policies to protect children from gun violence. In their appointments with >260 congressional leaders, physician advocates asked Congress for $50 million for the Centers for Disease Control and Prevention to research firearm safety and injury prevention. They also advocated for support for legislation aimed at universal background checks for gun ownership.[6] Four weeks later, the AAP held the Summit on Gun Injury Prevention and identified the following priorities: devoting resources to address poverty, advocating for federal standards to prevent children from accessing guns, and educating pediatricians about firearm safety and storage to be able to counsel patients and families appropriately.[7] As pediatric clinicians, we have a duty to support these policy agendas. We also have a responsibility to explore with our patients and their families fears and anxieties related to violence in their communities. Further assessment will determine if children and caregivers experience fear of violence differently and will identify the best clinical approach to address concerns unique to patients or their caregivers. As physicians explore these concerns, it is important to remember that just like any of the sensitive issues we screen for, if there is concern for immediate threat to a child's safety, mandated reporting to appropriate child protection agencies should occur as well as referrals for any necessary mental health expertise.

Each day at work, I am growing more and more comfortable with navigating difficult conversations with families, but I am unsure about how many more conversations I will sit through, feeling helpless that I cannot find a way to keep a loved one safe, even in their final days. Identifying concerns patients and families have about the risk of gun violence and supporting research for gun violence and legislation aimed at universal background checks are a couple of ways we all can do better, especially for our children, whose bravery and resolve keep me motivated each day at work.

ABBREVIATION

AAP: American Academy of Pediatrics

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