The benefits of lifesaving implantable cardioverter-defibrillator (ICD) therapy in pediatrics are well-recognized, with reduced mortality for survivors of cardiac arrest and those at potential risk for sudden cardiac death. Technological advances have allowed a reduction in the size of generators and improved defibrillation lead technology, expanding their use in younger patients. In addition, greater clinical understanding of inherited arrhythmia disorders and an increasing number of children with congenital heart disease surviving into adulthood have contributed to a growing population of young ICD recipients. Survival rates from sudden cardiac arrest in pediatric patients with ICDs have increased substantially. This has shifted the focus of research from mortality and clinical outcomes to evaluation of psychosocial factors related to the effect of living with an implanted cardiac device.

Because of the nature of their potentially life-threatening condition and unpredictability of arrhythmia presentation, patients with an ICD are at risk of developing psychological distress. Some patients with an ICDs will experience symptoms of anxiety, depression, and posttraumatic stress disorder (PTSD) as well as ICD device-related distress, such as worry about shocks. Factors that can influence the effect of these psychological disorders include sociodemographic variables, variables related to the ICD, and psychosocial variables. Younger patients appear to be at increased risk for frequent shocks, have more interruptions in their daily life, may be more cognizant of device appearance and cosmesis, develop more avoidant behaviors, and experience elevated anxiety levels. Studies examining psychosocial factors in pediatric patients with an ICDs found lower self-reported psychosocial and physical quality of life scores compared to healthy children, as well as increased anxiety associated with the presence of shocks and longer time since implantation. The largest study to date of pediatric patients with pacemakers and ICDs (n = 166) found that those with ICDs had a higher prevalence of anxiety disorders than did a normal population and that patients with more complex medical disease and those who are older at device implantation may have higher anxiety levels, regardless of whether they receive a pacemaker or ICD.

Parents of children with congenital heart disease (CHD) may also be at risk for mental health issues. Having a child with CHD can be emotionally overwhelming, in addition to the physical, financial, and practical challenges that are experienced. Psychological distress has been reported in 30%–80% of parents of a child with CHD, not necessarily related to the CHD severity. Findings also included that parent mental health, the parent-child relationship, and parental quality of life can all be affected. Mothers appear to be at higher risk for psychological distress, anxiety, depression, somatization, hopelessness, and PTSD than do fathers. A systematic review of 30 studies of parents of children with critical CHD found that 30% had symptoms consistent with PTSD, with 25%–50% reporting symptoms of anxiety and/or depression. Studies have shown a high prevalence of PTSD in parents of children with life-threatening diseases. However, it is yet unknown whether parents of children with cardiac rhythm devices develop stress symptoms or PTSD. A recent study of parents of children with cardiac rhythm devices found that in both parents, total PTSD symptom severity scores were a significant predictor for mental health dysfunction after controlling for child age at implantation, presence of other noncardiac disease in the child, parental age, and presence of their own chronic disease.

The incidence of PTSD in both pediatric patients with an ICDs and their parents is an important and emerging field of study. In this issue of Heart Rhythm Journal, Schneider et al address this understudied yet critical field. The mental health of children and adolescents with ICDs is as essential to understand and address as their physical health and cardiology care.

This novel study reports important data related to prevalence and factors associated with PTSD in pediatric patients with an ICDs and their parents. Incorporation of both patient and parent perspectives is an important contribution as most studies have not highlighted both. However, there are limitations that will lay the groundwork for future studies. The data collection tool administered (UCLA Child/Adolescent PTSD Reaction Index for DSM-IV) screens from a variety of subgroup exposures such as school violence, interpersonal violence, abuse, and/or serious mental health dysfunction after controlling for child age at implantation, presence of other noncardiac disease in the child, parental age, and presence of their own chronic disease.

Funding Sources: The authors have no funding sources to disclose.

Disclosures: The authors have no conflicts of interest to disclose. Address reprint requests and correspondence: Dr Charles I. Berul, Division of Cardiology, Children’s National Heart Institute, 111 Michigan Avenue NW, Washington, DC 20010. E-mail address: cberul@childrensnational.org.
accident. This study did not make a distinction between medical- or device-related psychological trauma and non–medical-related types of traumas; therefore, the specific effect of having an ICD is unknown. The authors’ aim was to determine the prevalence and factors associated with pediatric patients with ICDs and their parents and acknowledged that future studies should further explore device-related effect on PTSD.

Another limitation of the study approach is lack of a blanking period where questionnaires were not administered after crucial follow-up interventions such as generator change or recent shock. Studies have shown that levels of distress are higher during these unique time points, which can affect the meaning of the data. As the authors state, this is an area for future studies to better inform screening of patients with ICDs and parents at key time points.

There was a wide range of time since implantation from only 7 days to over 9 years, and it would have been interesting to learn whether there were important time-related variables in relation to implant or shocks. Webster et al. found differences in anxiety between those who have had their device for less than 6 months and those who have had it for longer at initial screening. The cross-sectional study design may not explain differences in PTSD findings in this broad time frame. Schneider et al. evaluated time since implantation with PTSD and found no variation between the PTSD and non-PTSD groups, which is valuable information. Future studies might add long-term measures to evaluate PTSD changes over time in patients/parents to further delineate differences in the endurance of PTSD over time.

The present study provides important data on PTSD prevalence and factors in pediatric patients with ICDs and their parents. Addition of these data to the current paucity in the literature is an excellent and significant foundation for larger multicenter studies, and the authors should be congratulated for their work. Future studies might consider including a comparison group to increase the generalizability of the findings. In addition, future studies can further elucidate the causative effect of having an ICD on PTSD in specific terms to discern if the device or the concurrent medical/non–medical factors/stressors play a more important role. While receiving an ICD does not always mean that one will receive a shock, the expectation is that approximately 20%–30% of pediatric ICD recipients will eventually get an appropriate or inappropriate shock. Just knowing this potential for getting a defibrillation shock might lead to the potential for developing an emotional shock, or PTSD. There is a crucial need for additional research on the development, related factors, extent, and duration of PTSD and other mental health issues in children with ICDs and their parents as well as for screening approaches and interventions that can be easily delivered in the clinical setting during routine cardiology care. These considerations should be planned before implanting devices in children with deliberate strategies for psychological support of patients and their parents for the long haul.

References