Posttraumatic stress disorder in pediatric patients with implantable cardioverter-defibrillators and their parents

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BACKGROUND An implantable cardioverter-defibrillator (ICD) in the pediatric patient (and the precipitating events that led to ICD placement) can be traumatic for patients and their families and may lead to posttraumatic stress disorder (PTSD).

OBJECTIVES This study aimed to estimate the prevalence of PTSD in pediatric patients with an ICD and their parents and identify the factors associated with PTSD incidence.

METHODS Pediatric participants with an ICD aged 8–21 years and parents of children aged 0–21 years completed surveys that included demographic characteristics and PTSD measures. Pediatric participants completed additional psychosocial measures, such as anxiety and depression self-report questionnaires.

RESULTS Fifty youth (30% female) and 43 parents (70% female) completed the measures. Six of 50 youth (12%) met the screening criteria for a likely PTSD diagnosis, while 20 of 43 parents (47%) met the cutoff for PTSD on the screening measure. Children with PTSD were more likely to have had a secondary prevention ICD (83% vs 17%; $P = .021$), meet the clinical cutoff for depression (67% vs 16%; $P = .005$), and had higher shock anxiety scores (31.7 vs 17.9; $P = .003$) than children without PTSD. Female gender (57% vs 23%; $P = .043$) and patient depression (31% vs 5%; $P = .042$) were associated with PTSD in parents.

CONCLUSION Parents were found to be more likely to meet the criteria for PTSD than youth. In youth, PTSD was associated with medical and psychosocial factors, whereas PTSD in parents was associated with being female and child depression. Clinic-based screenings and management planning of emotional functioning are warranted to address psychological distress in patients and parents.

KEYWORDS Pediatric; ICD; Psychological; PTSD; Family

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Introduction

An implantable cardioverter-defibrillator (ICD) can be a life-saving therapy. However, the life-threatening events leading to the decision to place these devices are stressful for patients and their families, and in many cases traumatic. These events place patients and families at risk for posttraumatic stress disorder (PTSD), a trauma- and stressor-related disorder with a distinct symptom cluster that includes intrusion symptoms, avoidance, negative alterations in cognitions and mood, and marked alterations in arousal and activity, appearing at least 1 month after experiencing a trauma.[1] It is important for the clinician to identify PTSD symptoms in this

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population as it can negatively affect medical outcomes and lead to further complications in patients.[2]

PTSD has been shown to predict poor medical care, including adherence to medications.[3] This ultimately can be reflected in clinical outcomes, with a substantial effect on survival, and a relative mortality risk 3-fold higher in those with PTSD.[2] Thus, it is critically important to identify in pediatric patients with ICDs and their parents to facilitate optimal medical care. While several studies have identified PTSD prevalence rates of 14%–36% in adults with ICDs, little work has been done in children, with a single study finding a prevalence of 4%.[2,4–7]

Other family members can also be affected by the need for an ICD in a child. Parents may witness the life-threatening event leading to ICD placement or have perceived guilt for inherited conditions, placing them at risk for adjustment issues as well. In a review of early traumatic stress in parents of children newly diagnosed with a serious illness or injury, rates of PTSD ranged from 8% to 68%.[8] A recent study found rates of PTSD in parents of children with either pacemakers or ICDs to be ~9%.[9]

In families with pediatric congenital heart disease, parental PTSD has been shown to lower quality of life ratings in both patients and parents.[10] There is a need to better understand rates and correlates of PTSD in both pediatric patients and their parents in order to triage interventions to improve both patient and parent functioning. This study aimed to evaluate the prevalence of and risk factors for PTSD in pediatric patients with ICDs and their parents.

Methods

Subjects

After approval from the institutional review board, pediatric patients with ICDs and parents were recruited in the electrophysiology clinic of Lucile Packard Children's Hospital at Stanford (Palo Alto, CA) and Valley Children's Hospital (Madera, CA), between December 2015 and January 2018. The research reported in this article adhered to the Helsinki Declaration as revised in 2013 guidelines. Inclusion criteria for participants included patient age between 8 and 21 years with ICD placement. Parents were included if their children were aged 0–21 years. Patients and parents were excluded if they were unable to complete the questionnaires in English or if the child had a developmental delay that would preclude them from being able to answer the questionnaire.

Assessments

Youth participants completed a comprehensive psychosocial battery, which included basic demographic questions, device acceptance questionnaires, and standardized measures of depression, anxiety, and PTSD (described below). Parents simultaneously completed a self-report measure of their own PTSD. The questionnaires were completed electronically on a tablet device in clinic either before, during, or after a single routine cardiology clinic visit. Youth and parents were asked to complete the questionnaires separately, without sharing their answers. Positive endorsement of suicidal thoughts on the Children's Depression Inventory (CDI) were flagged and addressed by a either a social worker or psychologist in the clinic to assess the safety risk and make appropriate referrals for mental health services. Study data were collected and managed using Research Electronic Data Capture electronic data capture tools hosted at the Stanford Center for Clinical Informatics.[11] After the completion of the psychosocial battery, additional demographic information and medical variables were extracted from the youth participants' medical records.

Measures

Standard measures of PTSD were administered to youth participants and parents, and additional standard measures of depression, anxiety, and device acceptance/anxiety were administered to youth. Self-report measures were used, given the ease of administering in a clinic environment and that this is commonly used in the adult psychosocial ICD studies.[4,5] The UCLA Child/Adolescent PTSD Reaction Index for *DSM-IV*, a valid and reliable measure for assessing PTSD in children and adolescents,[12,13] was administered to all child and adolescent participants. On this measure, participants first indicate whether they have experienced traumatic events and then if positive, they are presented with items assessing PTSD symptoms in the past month that correspond to diagnostic criteria.[12] The initial questions involving traumatic events were modified from the original format to accommodate a clinic-based screening (given the inability to provide immediate follow-up for items that could necessitate a reporting situation, such questions were removed, but a free text box, where any event could be included, remained). For all who endorsed having experienced a trauma, a psychologist scored the remaining responses according to the standardized scoring sheet.[12] Youth who met either partial (defined by meeting exposure to a traumatic event and 2 of the other domains: reexperiencing, avoidance, or increased arousal) or full (number of symptoms in all 4 domains) criteria were identified as likely having PTSD.[12] Parents were administered the PTSD Checklist –Civilian Version (PCL-C), a valid and reliable 17-item self-report screening measure reflecting the *Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition)* symptoms of PTSD.[14] The PCL-C asks about generic "stressful experiences."[15] A cutoff score can be calculated by summing the scores for each of the 17 items, which have responses of 1 – "Not at all" to 5 – "Extremely." A cutoff score of 30 is suggested for screening of a general population.[15]

The CDI is a 27-item self-report measure of depressive symptoms in youth that is valid, reliable, and widely used. Higher scores indicate more severe depressive symptoms, and scores of $\geq$15 indicate elevated depressive symptoms.[16] The State Trait Anxiety Inventory, a valid and reliable measure that consists of 40 items that assess both state (at the time of administration) and trait (more long-standing) anxiety,

Table 1 Patient sample characteristics (N = 50)

Characteristic	Full sample (N = 50)			With PTSD (n = 6)		Without PTSD (n = 44)		
	Mean (SD)	n (%)	Range	Mean (SD)	n (%)	Mean (SD)	n (%)	*P*
Patient age (y)	16.0 (3.3)		8–21	14.2 (5.5)		16.3 (2.9)		.001
Time since implantation (y) (n = 42)	2.87 (2.43)		0.02–9.3	1.65 (1.9)		2.99 (2.5)		.5
Female patient		15 (30.0)			3 (50)		12 (27)	.3
Diagnosis								
Primary arrhythmia		18 (36.0)			4 (67)		18 (41)	.2
Cardiomyopathy		22 (44.0)			1 (17)		17 (39)	.3
Congenital heart disease		10 (20.0)			1 (17)		9 (20)	.8
Prevention								
Primary		30 (60.0)			1 (17)		29 (66)	.021
Secondary		20 (40.0)			5 (83)		15 (34)	.021
On β-blocker		38 (76.0)			6 (100)		32 (73)	.1
Ever received a shock? (n = 49)		12 (24.5)			1 (17)		12 (27)	.6
Number of shocks received (n = 48)								
0		37 (77.1)						
1		6 (12.5)						
2		4 (8.3)						
3		0 (0.0)						
4		1 (2.0)						
Depression (CDI) score	8.6 (7.3)		0–31	15.8 (6.8)		7.5 (6.9)		.1
Anxiety (STAI) score	35.2 (9.6)		20–63	37.2 (9.4)		35 (9.6)		.8
Florida Shock Anxiety Scale score (n = 47)	19.3 (10.2)		10–46	31.7 (14.6)		17.9 (10.2)		.003
Florida Patient Acceptance Survey score (n = 47)	56.7 (9.6)		38–73	51.4 (12.2)		57.3 (9.2)		.4

CDI = Children's Depression Inventory; PTSD = posttraumatic stress disorder; STAI = State Trait Anxiety Inventory.

yields a score between 20 and 80, with higher scores reflecting more severe anxiety symptoms, and scores of ≥39 indicating clinically significant levels of symptoms.[17] Categorical variables on these measures were used given the clinical utility of meeting a cutoff score.

Further, device-specific measures were administered to youth participants to assess shock anxiety and ICD device acceptance. The Florida Shock Anxiety Scale (FSAS), a reliable and valid measure of shock anxiety in adults with ICDs that results in a single score, was administered.[18] Higher scores on this scale represent greater shock anxiety.

The Florida Patient Acceptance Survey (FPAS), a self-report measure of the acceptance of cardiac implantable devices that has demonstrated good internal consistency and validity in adults, was administered.[19] The measure includes 4 factors: return to function, device-related distress, positive appraisal, and body image concerns, and higher scores represent greater device acceptance.[19] A question on the FSAS and FPAS was modified for a pediatric population (from sexual activity to kissing and holding hands with loved ones), as previously done by Cuttita.[20]

Statistical analyses

Descriptive statistics were calculated for demographic and medical variables as well as patient and parent self-report measures. Data are presented as number (percentage) for categorical values and mean ± SD or median (interquartile range) for continuous variables. Independent-samples *t* tests and χ^2 analyses were used to compare individuals who met the cutoff for PTSD based on demographic characteristics (eg, participant age and gender), medical factors (eg, number of discharges, type of ICD, and time since implantation), and psychosocial factors (eg, scores on the FPAS and FPAS, depression, and anxiety). The McNemar test was used to assess whether youth whose parents met the cutoff for PTSD was more likely to also meet the PTSD cutoff than youth with parents without PTSD. Analyses were performed using SPSS version 25 (IBM Corporation, Armonk, NY) with pairwise deletion to handle missing data. All *P* values <.05 were considered significant.

Results

Sample characteristics

The patient sample consisted of 50 youth between the ages of 8 and 21 years who completed PTSD measures. Fifteen of 50 (30%) were female. The mean age was 16.0 ± 3.3 years, and youth had been followed after ICD implantation for an average of 2.9 ± 2.4 years. Twenty of 50 (40%) ICDs were placed for secondary prevention, and 12 of 50 (25%) youth participants had received an ICD discharge. Additional youth characteristics are listed in Table 1.

The parent sample included 43 parents. Thirty of 43 (70%) were female. Their affected children were between the ages of 7 months and 21 years, with a mean age of 13.9 ± 5.2 years. These youth had been followed after ICD implantation for an average of 2.4 ± 2.4 years. Sixteen of 43 (37%) of ICDs were placed for secondary prevention; and 6 of 43

Table 2 Parent sample characteristics (N = 43)

Characteristic	Full sample (N = 43)			With PTSD (n = 20)		Without PTSD (n = 23)		
	Mean (SD)	n (%)	Range	Mean (SD)	n (%)	Mean (SD)	n (%)	*P*
Patient age (y)	13.9 (5.2)		0–21	12.55 (4.97)		15.04 (5.2)		.8
Time since implantation (y) (n = 40)	2.4 (2.4)		0.1–9.3	2.82 (2.66)		2.14 (2.26)		.6
Female patient		30 (69.8)			6 (30)		7 (30)	.9
Diagnosis								
Primary arrhythmia		24 (55.8)			12 (60)		12 (52)	.6
Cardiomyopathy		13 (30.2)			6 (30)		7 (30)	.9
Congenital heart disease		6 (14.0)			2 (10)		4 (17)	.5
Prevention								
Primary		26 (60.5)			11 (58)		15 (65)	.6
Secondary		16 (37.2)			8 (42)		8 (34)	.6
On β-blocker		32 (74.4)			16 (80)		16 (70)	.4
Ever received a shock?		6 (14.0)			3 (15)		3 (13)	.8
Number of shocks received								
0		37 (86.0)						
1		4 (9.3)						
2		1 (2.3)						
3		0 (0.0)						
4		1 (2.3)						
Depression (CDI) score (n = 35)	8.2 (7.2)		0–31	10.04 (9.1)		6.61 (4.8)		.189
Anxiety (STAI) score (n = 35)	33.9 (8.2)		20–51	32.67 (8.9)		34.81 (7.9)		.6
Florida Shock Anxiety Scale score (n = 33)	19.6 (11.0)		10–46	20.6 (12.3)		18.8 (10.2)		.7
Florida Patient Acceptance Survey score (n = 33)	57.6 (9.9)		38–73	58.4 (10.4)		56.9 (9.7)		.9

CDI = Children's Depression Inventory; PTSD = posttraumatic stress disorder; STAI = State Trait Anxiety Inventory.

(14%) youth had received an ICD discharge. Additional characteristics of the parent sample are listed in Table 2.

Rates of PTSD and its correlates

Six of 50 youth (12%) met full (n = 5) or partial (n = 1) criteria for PTSD, and 20 of 43 parents (47%) met or exceeded the cutoff score for PTSD. Within the 34 youth-parent dyads, only 3 of 34 dyads (9%) had both youth and parent with PTSD while 17 of 34 (50%) dyads had neither the youth nor the parent with PTSD. Youth whose parents met the clinical cutoff for PTSD were more likely to also meet the PTSD cutoff than youth with parents without PTSD (19% vs 6%; $P = .002$).

Comparisons of demographic, medical, and psychosocial variables based on meeting PTSD criteria revealed several significant differences. Youth who endorsed a medical-related trauma (n = 4) were more likely to have PTSD than those who did not endorse a medical trauma (n = 7) (67% vs 16%; $P = .005$), and youth with secondary prevention were far more likely to meet PTSD criteria than those with primary prevention (83% vs 17%; $P = .021$). Youth with PTSD were significantly more likely to be over the CDI cutoff than those without PTSD (67% vs 16%; $P = .005$). Although having had a shock did not significantly relate to PTSD (17% vs 27%; $P = .6$), youth with PTSD had significantly higher shock anxiety scores than did those without PTSD (31.7 vs 17.9; $P = .003$).

Although gender was unrelated to youth PTSD (50% vs 27%; $P = .3$), female parents were significantly more likely to have PTSD than male parents (85% vs 57%; $P = .043$). Similar to youth PTSD, parents with PTSD were more likely to have a child exceeding the CDI cutoff for depression (31% vs 5%; $P = .042$). Youth endorsed medical-related trauma (50% vs 50%; $P = .8$) and ICD prevention type (58% vs 65%; $P = .6$) were unrelated to parent PTSD. Youth participants' underlying cardiac diagnosis type, type of device, history of receiving a shock, number of shocks, time since implantation, youth age and gender, general (not shock-specific) anxiety, and parent acceptance were not related to PTSD in either parents or youth.

Discussion

The decision to implant an ICD is surrounded by stressful circumstances. Patients have either had a life-threatening event or received a potentially lethal diagnosis. This often results in psychological distress in patients and parents alike. For some, this distress actually causes a trauma, resulting in symptoms associated with PTSD. In adult patients with ICDs, PTSD rates can be as high as 14%–36%.[2,4–6] Precise rates of and factors related to PTSD in pediatric patients with ICDs have been understudied. Therefore, this study aimed to both identify the prevalence of PTSD in pediatric patients with ICDs and their parents and examine the factors associated with PTSD symptoms. In this sample, 12% of patients met full or partial criteria for PTSD, which is higher than the rates previously described by Webster et al,[7] in which only 4% of pediatric patients met criteria.

The discrepancy between our study and the study by Webster may be related to timing of psychosocial assessment, as Webster excluded patients who had devices placed within 6 months of assessment.

Twenty-two percent of our patients indicated that the traumatic event they experienced was specifically related to their medical condition, and endorsement of this trauma was associated with PTSD. Although it is unclear whether diagnosis, surgery, cardiac arrest, or another specific factor and/or a combination of these factors lead to PTSD, our findings suggest that medical trauma related to their need for an ICD put these patients at risk for PTSD.

In keeping with medical trauma influencing the likelihood of PTSD, patients with secondary prevention ICDs were far more likely to experience PTSD symptoms than patients who had primary prevention ICDs (83% vs 17%). While patients often do not have a recollection for the event itself, they are often affected by knowing that they had a near-death experience. In an adult ICD sample, Rahmawati et al[21] found that patients with primary prevention ICDs had higher rates of anxiety and worries about the ICD but found no difference for PTSD between prevention groups. This discrepancy suggests that age and emotional development may have an influence, but further studies in both children and adults are needed to draw such a conclusion. Patients with PTSD were more likely to have higher shock anxiety scores on the FSAS, which assesses one's avoidance of activities associated with shock and also anxiety or uncertainty of shocks.[22] While not the sole driver of PTSD, this suggests that anxiety about shocks can be triggering to the ongoing nature of trauma. Those experiencing high shock anxiety may be at elevated risk for PTSD. Data on recent hospitalizations, time since shocks, and detailed time since implantation were not collected, and this could affect the levels of PTSD/other variables.

We felt it essential to also assess parental function as medical conditions affect the entire family. Prior research indicates that parents' mental health influences a child's functioning.[10] In our study, nearly half of parents (47%) experienced PTSD. This is in contrast to a study of pediatric patients with a pacemaker and those with an ICD by Werner et al,[9] in which 9% of parents met either full or partial criteria for PTSD on a self-report measure. This may be explained by the fact that there were few patients with ICDs in the Werner study, as 80% of patients had a pacemaker.[9] Other close comparisons of parents of children with heart transplant or congenital heart disease find 20%–30% of parents with PTSD.[23,24]

It is striking that parents of patients with ICDs had such high rates of partial/full criteria for PTSD. While this may be related to differences in measure selection, it does suggest that the experience of having a child with an ICD can be quite traumatic. The mere presence of PTSD symptoms in parents is meaningful, given the known effect it can have on patient quality of life,[10] regardless of whether it is attributed to their child's medical condition.

The results also suggest the influence of parent PTSD on youth PTSD, as children whose parents met the clinical cutoff for PTSD were more likely to also meet the PTSD cutoff than children with parents without PTSD. When examining the broader child trauma literature, differences in assessment and types of trauma experienced make it difficult to draw conclusions with former studies. An ongoing need exists to better understand the influence of parent trauma symptoms on child trauma symptoms, recognizing the effect medical diagnoses and treatment can have on a family unit.[25]

Further examining family factors, we also found that mothers are at higher risk for PTSD than fathers. This finding is congruent with research in the general population, which supports that the lifetime prevalence of PTSD is higher for women than for men. Specifically in parents of children and adolescents with physical illness, higher rates of PTSD symptoms are seen in mothers rather than in fathers.[26] It is common that mothers of patients with chronic illness are more likely to take on caregiving responsibilities and therefore accompany their child to the clinic and complete the screen.[27] If the parent had PTSD associated with the child's medical condition, tasks associated with caregiving for a child with a chronic medical condition may be triggering and affect the rates we found in mothers. Interestingly, there was no difference for parent PTSD between prevention groups.

Patient depression was the only factor related to both patient and parent PTSD. The link between patient depression and both patient and parent PTSD is likely bidirectional. Comorbidity between depression and PTSD exists in the general adult population.[28] However, our findings expand this area of research to suggest that patient depression and parent PTSD may be mutually influential as well. These findings reinforce and expand the utility of routine depression screenings as a standard practice within general cardiology care and ICD follow-up care, specifically. The differences in both prevalence rates and correlates of PTSD in patients and parents suggest that separate screenings for patients and parents can provide critical and distinct information that might otherwise go overlooked. Improved consistent screening will aid in detecting those patients or parents struggling with trauma symptoms, so that they can hopefully be connected to mental health practitioners who can implement interventions to reduce their distress. Moreover, continued research that examines the relationship between time since critical events such as implantation, shock, and generator change and occurrence of psychological distress would inform when screening should occur to best support patients. This is in line with recent recommendations to first stratify patients with ICDs according to identified psychological distress and then provide evidence-based therapies to those exceeding cutoffs, with the goal of improving the lives of patients in distress.[29,30]

Limitations

Our study had several limitations. This was a small study that limits statistical analysis. The observational and cross-sectional nature of our research design restricts our ability

to draw any causal conclusions about the observed associations between PTSD and demographic, medical, and psychosocial factors. Moreover, our study included self-report measures, which differ from the Webster's prior study that used diagnostic interviews.[7] Self-report measures are commonly used in adult ICD samples and pediatric medical clinics for feasibility purposes as the first step in screening for symptoms[2,6,31] and are then typically followed by a detailed clinical interview to confirm diagnosis. The lack of the specific trauma the parent experienced on the PCL-C limits our understanding, and including this in future studies will be essential. Additionally, the majority of the parents in our sample were mothers or female caretakers, which may limit the generalizability of our findings to fathers or male caretakers. Finally, there was no comparison group, which limits the ability to generalize findings.

Conclusion

Our study estimates the prevalence of PTSD in this single-center sample of pediatric patients with ICDs and their parents. For both patients and parents who experience PTSD, clinical attention is warranted given the potential effect on medical outcomes. While parents were more likely to experience PTSD than patients, identifying PTSD in patients is important, particularly for patients with medical trauma or secondary prevention ICDs. Clinical practice may be improved by mental health screening of patients and parents in order to connect them with mental health services to address previously unidentified needs. ICDs equip patients with a lifesaving mechanism, and attention to those affected by mental health conditions will allow for patients to thrive more fully. Similarly, given the effect that parental mental health can have on children, attention to parents of this patient population is justified and doing so will offer true family focused care.

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