

Perceptions of an Implantable Cardioverter-Defibrillator: A Qualitative Study of Families with a History of Sudden, Life-Threatening Cardiac Events, and Recommendations to Improve Care

Jarrett Linder, MD, MS,¹ Nadia Hidayatallah, PsyD,² Marina Stolerman, PsyD,³ Thomas V. McDonald, MD,⁴ Robert Marion, MD,⁵ Christine Walsh, MD,⁵ and Siobhan M. Dolan, MD, MPH⁶

¹University of Chicago, Comer Children's Hospital, Chicago, IL. ²Department of Psychiatry, St. Luke's Roosevelt Hospital Center, New York, NY. ³Private Practice, New York, NY. ⁴Departments of Medicine and Molecular Pharmacology, Albert Einstein College of Medicine/Wilf Family Cardiovascular Research Institute, Bronx, NY. ⁵Department of Pediatrics, Children's Hospital at Montefiore/Albert Einstein College of Medicine, Bronx, NY. ⁶Department of Obstetrics & Gynecology and Women's Health, Albert Einstein College of Medicine/Montefiore, Bronx, NY.

Objective: To identify major concerns associated with implantable cardioverter-defibrillators (ICDs) and to provide recommendations to adult and pediatric physicians involved in the care of patients with ICDs.

Background: Cardiac ion channelopathies are a well-recognized cause of sudden cardiac death in infants, children, adolescents, and young adults. ICDs are effective in preventing sudden death from fatal arrhythmias in patients with known cardiac channelopathies. There is a paucity of research on the effect of ICDs on quality of life in patients with cardiac channelopathy diagnoses, especially young patients.

Methods: A qualitative study interviewing patients and families affected by inherited arrhythmias was conducted. Fifty participants with personal or family histories of cardiac events or sudden death were interviewed individually or in focus groups by clinical psychologists. All interviews were transcribed verbatim and then analyzed and coded

based on current qualitative research theory to identify themes related to the research question. Twenty-four participants discussed ICDs in their interviews.

Results: Participants reported concerns about ICDs, and these concerns were categorized into six themes: (1) comprehension and physician-patient communication; (2) anxiety; (3) restrictions and fallacies; (4) complications; (5) utility; and (6) alternative therapy. Participants noted communication breakdowns between providers and their colleagues, and between providers and their patients. Participants and their families experienced many different forms of anxiety, including worry about the aesthetics of the ICDs and fears of being shocked. Multiple restrictions, fallacies, and complications were also cited.

Conclusion: Interview themes were used to formulate recommendations for counseling and educating patients with ICDs.

INTRODUCTION

Ventricular tachyarrhythmias are the most common cause of sudden cardiac death (SCD). Among ventricular tachyarrhythmias, primary and secondary ventricular fibrillation represent the major causes of SCD (Bayés de Luna, Coumel, & Leclercq, 1989). Cardiopulmonary resuscitation may preserve brain function and prevent end organ damage temporarily; however, the only effective treatment for ventricular fibrillation is prompt electrical defibrillation. Implantable cardioverter-defibrillators (ICDs) are more effective than anti-arrhythmic agents for the secondary prevention of SCD, especially after a previous life-threatening cardiac event. ("A Comparison of Antiarrhythmic-Drug Therapy," 1997; Akhtar et al., 1993; Connolly et al., 2000; Kuck, Cappato, Siebels, & Ruppel, 2000). Evidence has supported the use of ICDs as a treatment modality for secondary prevention in patients with a history of ventricular tachycardia, ventricular fibrillation, or successful resuscitation from SCD, and for primary prevention in patients at severe risk for developing ventricular tachycardia, ventricu-

lar fibrillation, or both (Epstein et al., 2008).

Significant causes of ventricular tachycardia and ventricular fibrillation are the congenital cardiac channelopathies, including long QT syndrome (LQTS), Brugada syndrome (BS), catecholaminergic polymorphic ventricular tachycardia (CPVT), and short QT syndrome (SQTS). Cardiac channelopathies, inherited in an autosomal dominant pattern with variable penetrance, present with a range of phenotypes. Channelopathies are potentially lethal, with reports of 6% to 13% of individuals with LQTS experiencing cardiac arrest or SCD before the age of 40 if not treated (Modell & Lehmann, 2006). Many patients are asymptomatic until their initial clinical manifestation of sudden death. In addition, 25% of patients with LQTS have "concealed" phenotypes in which they are at risk for cardiac arrhythmias but do not have prolonged QT intervals on electrocardiograms (Goldenberg et al., 2011). Cardiac channelopathies produce ventricular tachyarrhythmias via the abnormal conduction of ions through affected ion channels responsible

for depolarizing and repolarizing the cardiac myocyte cell membrane, resulting in abnormal electrical conductance throughout the heart. These channel abnormalities are inherited as gain-of-function or loss-of-function mutations in families, placing first-degree relatives of affected individuals at considerable risk of inheriting the same genetic mutations. Therefore, genetic testing has emerged as a useful screening tool for identifying cardiac channelopathies in patients and their families with a strong clinical suspicion of this diagnosis (Boussy et al., 2010).

Evidence suggests that LQTS, BS, CPVT, and SQTs are significant causes of SIDS and SUDS (Arnestad et al., 2007; Tester & Ackerman, 2009). Sudden infant death syndrome (SIDS) is defined as the sudden death of a child under the age of 12 months with no identifiable medical cause after a thorough investigation. Sudden unexplained death syndrome (SUDS) refers to the unexplained death of a person between the ages of 1 and 25, 30, 35, or 40 (depending upon the source). Sudden unexplained death in childhood (SUDC) applies to the sudden death of a child between the ages of 1 and 18. Therapy for cardiac channelopathies often involves primary and secondary prevention of ventricular tachyarrhythmias through the implantation of ICDs, along with beta blocker therapy and lifestyle modification (Kaufman, 2009).

Complication rates related to ICDs have been reported at approximately 30%. Surgical complications, generator-related problems, lead complications, and inappropriate shocks have been identified as the most common complications (Alter, Waldhans, Plachta, Moosdorf, & Grimm, 2005). Similar complications have been identified in the pediatric population, with the addition of a significant psychosocial impact on patients' lives (Shah, 2009).

There is a paucity of research investigating the effect of ICDs on the quality of life of patients with cardiac channelopathy diagnoses, especially young patients. As part of a larger qualitative study of patients and families primarily affected by inherited arrhythmias to investigate the ethical and social issues associated with genetic testing, we performed a secondary analysis on the impact of ICDs. In their comments, participants often spontaneously raised issues related to ICDs. A secondary analysis of the data identified themes associated with ICDs. This study identifies important topics for healthcare providers to discuss with their patients living with or considering ICD placement.

METHODS

Recruitment of Families

This study is an analysis of comments voiced by a subset (24 out of 50) of the subjects enrolled in the Montefiore Einstein Center for CardioGenetics' study on the ethical issues raised by the translation of genetic knowledge into clinical practice. The subjects were chosen for the subset if they spontaneously mentioned ICDs in their interviews or focus groups. The original study focused on evaluating

and organizing ethical, legal, and social issues associated with cardiogenetic diseases linked to potentially fatal cardiac arrhythmias (Barlevy et al., 2012; Cohen et al., 2012). Fifty participants were interviewed individually or in focus groups to learn about their subjective experience of having a cardiogenetic disease. Associated ethical and social issues were evaluated. All participants in the study had histories, either personal or family, of cardiac events with clinical diagnoses of cardiac arrhythmia, or of relatives who had died from SIDS or SUDS.

The study population was recruited from three different sources: patients being cared for at the Montefiore Einstein Center for CardioGenetics (n = 27); respondents to an invitation posted in a newsletter from the Sudden Unexplained Death in Childhood Program (n = 9); and respondents to an invitation posted in a newsletter from the Sudden Arrhythmia Death Syndromes Foundation (n = 14). Prior to study participation, each recruited individual provided written informed consent and completed a questionnaire containing demographic information. The study protocol was reviewed and approved by the Institutional Review Board of Albert Einstein College of Medicine/Montefiore Medical Center.

Interviews and Transcription

All interviews and focus groups were conducted by clinical psychologists either in person or over the telephone. Open-ended questions were used to promote discussion about participants' experiences with cardiac arrhythmias or sudden death. Focus groups were composed of two or more unrelated individuals. Interviews were conducted with individuals and family units. All interviews and focus groups were recorded with audio devices and were subsequently transcribed verbatim. Transcripts were de-identified to protect participants' privacy. For the present study, comments were identified and extracted that were specifically relevant to the participants' experiences with ICDs.

Coding and Analysis of Transcripts

The transcripts from this study as well as the parent study were analyzed by the grounded theory approach developed by Auerbach and Silverstein (2003). This approach groups regularly used words and phrases from different interviews or focus groups into repeating ideas, and then groups these similar repeating ideas into themes, further describing the research question.

Statistical Analysis

A chi-square test was performed comparing the subjects included in the ICD study to the subjects excluded from the study.

RESULTS AND DISCUSSION

Participant Population and Demographics

Demographic information for the entire population and the participants who discussed ICDs is provided in Table 1. Thirty-nine women and 11 men participated in the overall study, and 21 women and three men discussed ICDs.

Table 1 | Demographic Characteristics of All Participants

Characteristics	Total Number of Participants	Participants Who Discussed ICDs	Participants Who Did Not Discuss ICDs	χ^2 p-value for ICD Study v. Excluded
	(n = 50)	(n = 24)	(n = 26)	
Sex				p = 0.119
Male	11 (22.0%)	3 (12.5%)	8 (30.8%)	
Female	39 (78.0%)	21 (87.5%)	18 (69.2%)	
Age				p = 0.698
< 20	1 (2.0%)	0 (0.0%)	1 (3.8%)	
21–30	9 (18.0%)	6 (25.0%)	3 (11.5%)	
31–40	9 (18.0%)	3 (12.5%)	6 (23.1%)	
41–50	14 (28.0%)	7 (29.2%)	7 (26.9%)	
51–60	11 (22.0%)	5 (20.8%)	6 (23.1%)	
> 60	6 (12.0%)	3 (12.5%)	3 (11.5%)	
Race				p = 0.560
African American	7 (14.0%)	3 (12.5%)	4 (15.4%)	
White	42 (84.0%)	20 (83.3%)	22 (84.6%)	
Asian	1 (2.0%)	1 (4.2%)	0 (0.0%)	
Ethnicity				p = 0.396
Latino/Hispanic	10 (20.0%)	6 (25.0%)	4 (15.4%)	
Non-Latino/Hispanic	40 (80.0%)	18 (75.0%)	22 (84.6%)	
Education				p = 0.166
Less than Ninth Grade	1 (2.0%)	1 (4.2%)	0 (0.0%)	
GED	2 (4.0%)	2 (8.3%)	0 (0.0%)	
High School	5 (10.0%)	4 (16.7%)	1 (3.8%)	
Some College	12 (24.0%)	4 (16.7%)	8 (30.8%)	
College Degree	12 (24.0%)	6 (25.0%)	6 (23.1%)	
Graduate Degree	15 (30.0%)	7 (28.0%)	8 (30.8%)	
Unknown	3 (6.0%)	0 (0.0%)	3 (11.5%)	
Marital Status				p = 0.139
Married	27 (54.0%)	15 (62.5%)	12 (46.2%)	
Cohabiting	2 (4.0%)	0 (0.0%)	2 (7.7%)	
Separated	2 (4.0%)	2 (8.3%)	0 (0.0%)	
Divorced	1 (2.0%)	0 (0.0%)	1 (3.8%)	
Widowed	3 (6.0%)	0 (0.0%)	3 (11.5%)	
Single	15 (30.0%)	7 (29.2%)	8 (30.8%)	
Annual Household Income				p = 0.032
< \$25,000	6 (12.0%)	4 (16.7%)	2 (7.7%)	
\$26,000–\$50,000	6 (12.0%)	5 (20.8%)	1 (3.8%)	
\$51,000–\$80,000	10 (20.0%)	7 (29.2%)	3 (11.5%)	
> \$80,000	21 (42.0%)	7 (29.2%)	14 (53.8%)	
Refused	2 (4.0%)	1 (4.2%)	1 (3.8%)	
Unknown	5 (10.0%)	0 (0.0%)	5 (19.2%)	

A chi-square analysis was performed comparing ICD discussants and nondiscussants, and the populations were found to be similar. Among those who discussed ICDs, two participants had diagnoses of Brugada syndrome, 19 participants had diagnoses of long QT syndrome, two participants had diagnoses of short QT syndrome, and one participant did not have a diagnosis. Of these participants, 10 had undergone ICD implantation, while 14 had not. Among those participants who had not elected to have ICDs placed, 42% were parents of children with ICDs and were intricately involved in the decision-making process (Table 2).

Identified Themes

Multiple themes were identified during the discussion. Themes identified include comprehension and physician-patient communication, anxiety, complications, restrictions and fallacies, utility, and alternative therapy (Table 3 - 5).

Many ICDs were implanted in participants during or after emergency situations in which the participants had experienced life-threatening arrhythmias. During these circumstances, participants often expressed fear of the emergency surgery and noted that they were unsure of what was happening:

"The last thing I remember is turning on the TV to watch a movie. . . . I woke up, EMS was there. . . . I didn't know what was going on and [the doctors] told me I had to have the pacemaker placed. I was really scared." Female, age 29

The gravity of the situation often required urgent, rapid device implantation. Participants and their family members were often frightened and had difficulty comprehending the situation:

"[F]irst thing I remember hearing from the doctor was they had to put a defibrillator/pacemaker. . . . You gotta explain to me . . . talk to me in plain English. . . . I'm thinking my daughter is dying here." Female, age 51

Furthermore, participants and family members often did not completely understand the cardiac channelopathies and their treatments. Many participants used the terms "ICD" and "pacemaker" interchangeably and could not provide a clear distinction between the two:

"When [the doctor] explained it to me, in my mind [I thought], 'My 7-year-old needs a pacemaker?' I mean defibrillator, pacemaker—in my mind it's the same thing. Only 80-year-olds need that, not my 7-year-old." Female, age 29

Another issue raised by participants involved communication with medical staff. Many participants expressed dissatisfaction when asking hospital staff to listen and comply with their decisions. One member of a family who was well known to the hospital staff due to the previous loss of a child from SUDS commented:

Table 2 | ICD Study Participant Diagnoses and Presence/Absence of ICDs

Characteristics	Number of Participants (n = 24)
Diagnosis*	
BS	2 (8.3%)
LQTS	19 (79.2%)
SQTS	2 (8.3%)
Unknown	1 (4.2%)
ICD	
Yes	10 (41.7%)
No	14 (58.3%)
Child with ICD	6 (42.9%)
No Child with ICD	8 (57.1%)

*Patient diagnoses are listed: Brugada syndrome (BS), long QT syndrome (LQTS), short QT syndrome (SQTS), and unknown diagnoses. Presence or absence of an internal cardioverter-defibrillator (ICD) is listed for the participants. Participants without ICDs but with children who have ICDs are also listed.

"My daughter ran into a tree [while driving] and doesn't remember [the accident]. . . . [The paramedics] told us to go to the emergency room and get an EKG. . . . The doctors recognized me and our name . . . one simple EKG turned into an overnight stay in the ICU. . . . [The cardiologist] was going to put in a defibrillator right then and there and I said, 'No! We have an electrophysiologist.'" Female, age 46

Another woman described an encounter with medical staff regarding her ICD and her prior experiences with inappropriate shocks:

"I got to the hospital. . . . I told [the staff] that I have this device and my heart is not slowing down. And [the nurse told me] to breathe. And I told her it's not working. It's going to shock me. . . . As soon as I saw the [heart-rate monitor] get up to 170, 176 hit. I braced myself . . . and it shocked me. . . . They have medication that slows down your heart!" Female, age 30

Some participants described miscommunication between patients and medical staff, while others described communication breakdowns among providers within the medical community:

"[The doctors] felt that R had Brugada syndrome and the only way to prevent another event was to put in an ICD. . . . [The doctors] said we need to go ahead and not wait for the genetic test to come back, he needs an ICD. . . . [Years later] the neurology department . . . determined that [my son] actually had a seizure. . . .

Electrocardiologists [now] think there is nothing wrong with R's heart; it was a misdiagnosis. I wish they would have slowed down. . . . We didn't know; as parents we were scared to death." Female, age 58

Another participant reported further perceived dissension:

"Originally, [the physicians] were suggesting a pacemaker. . . . [O]nce [the genetic testing] came back negative, [the physicians] were pretty much writing [my disease] off." Female, age 25

Despite some examples of communication breakdown between physicians and their colleagues as well as physicians and their patients, effective physician-patient interactions led to improved medical knowledge and insight into other participants' diseases:

"[The doctors] placed the defibrillator . . . [as a] safety measure; were my heart to stop, [the ICD] would activate, give me a jump start and give me an opportunity to live through [the arrhythmia]." Female, age 55

"I have LQT1, which is more benign. . . . If I had [LQT subtype] 2, 3, or 4 [the doctors] would really insist that I get the ICD." Female, age 34

Patients who sought second and third opinions concerning their diagnoses, and received consistent recommendations from cardiologists as well as geneticists, appeared to have a better understanding of their disease and appeared more satisfied with the treatment, which in many cases was to receive an ICD:

"I got about three different doctors' opinions. I saw the genetic group. . . . [The physicians agreed] I should go [get the ICD placed]. . . . I'm looking at all my options and I said, 'Just get it, you never know, might save your life.'" Female, age 52

"[M]y QT interval was around 600. . . . It was very much a long QT syndrome. . . . I went through several doctors . . . they all said I should get the ICD." Female, age 24

Contemplating receiving and living with ICDs caused multiple types of anxiety in participants. Proband anxiety refers to those fears experienced primarily by the patient who had the ICD or was contemplating receiving an ICD himself or herself. Caregiver anxiety describes fears specific to parenting, with the caregiver having a heritable channelopathy himself or herself, or having an affected child. Finally, relative/friend anxiety represents the concerns of those close to an affected proband.

After being diagnosed with familial cardiac channelopathies, participants often considered having ICDs placed. One of the most common anxiety-producing thoughts was the concept of having a foreign device inside one's body forever. To many, this was an extremely scary thought with a constant reminder:

"[The ICD] feels weird. Once in a while when you feel the bump, and you know that's not actually supposed to be there." Female, age 52

"The ICD to me was really scary. I thought of cutting my body open and putting this titanium box in [my body] . . . seemed so freaky and alien to me." Female, age 34

Table 3 | Comprehension and Physician-Patient Communication Theme Identified and Described with Examples

Theme	Description	Example
Comprehension and Physician-Patient Communication	Emergency Situation	<ul style="list-style-type: none"> "[F]irst thing I remember hearing from the doctor was they had to put a defibrillator/pacemaker. . . . You gotta explain to me . . . talk to me in plain English. . . . I'm thinking my daughter is dying here." Female, age 51
	ICD Definition	<ul style="list-style-type: none"> "When [the doctor] explained it to me, in my mind [I thought], 'My 7-year-old needs a pacemaker?' I mean defibrillator, pacemaker—in my mind it's the same thing. Only 80-year-olds need that, not my 7 year-old." Female, age 29
	Communication Breakdown	<ul style="list-style-type: none"> "Originally, [the physicians] were suggesting a pacemaker. . . . [O]nce [the genetic testing] came back negative, [the physicians] were pretty much writing [my disease] off." Female, age 25
	Improved Patient Insight	<ul style="list-style-type: none"> "[The doctors] placed the defibrillator . . . [as a] safety measure; were my heart to stop, [the ICD] would activate, give me a jump start and give me an opportunity to live through [the arrhythmia]." Female, age 55
	Multiple Physician Opinions	<ul style="list-style-type: none"> "I got about three different doctors' opinions. I saw the genetic group . . . [The physicians agreed] I should go [get the ICD placed]. . . . I'm looking at all my options and I said, 'Just get it, you never know, might save your life.'" Female, age 52

Table 4 | Anxiety Themes Identified and Described with Examples

Anxiety Theme*	Description	Example
Proband	Foreign Device	<ul style="list-style-type: none"> “The ICD to me was really scary. I thought of cutting my body open and putting this titanium box in [my body] . . . seemed so freaky and alien to me.” Female, age 34
	Aesthetics	<ul style="list-style-type: none"> “I am a small person. [My ICD] is very pronounced. A friend of mine wanted to see it after I had the surgery. I said, ‘Just don’t gasp.’ I showed her and [my friend] was like, ‘ahhhh. . . .’ I told you not to gasp!” Female, age 46
	Shocks	<ul style="list-style-type: none"> “ICDs have killed people misfiring and having an event from your ICD. . . . I was feeling so scared and nervous.” Female, age 46
Caregiver	Dependence	<ul style="list-style-type: none"> “I do most of the parenting. . . . [W]hat if something happened to me and I had this little 3-year-old?” Female, age 46
	Change of Opinion with Family	<ul style="list-style-type: none"> “I had just had kids and I started thinking, ‘If I have short QT, then I want to be able to be around as long as I can for my children.’” Female, age 25
	Witnessed Event	<ul style="list-style-type: none"> “[S]he went on a vacation with the family, and the defibrillator went off twice. . . . All she could remember was seeing her kids scream. . . . [W]hat got her more afraid were the two little guys there watching her go through this.” Female, age 52
	Affected Child	<ul style="list-style-type: none"> “[My daughter] is very active . . . always bouncing. How do I say to her, ‘I’m afraid you might die?’” Female, age 29
Friend/Relative	Support System	<ul style="list-style-type: none"> “She gets scared her device is gonna go off, so I’ll go over there, but I’m scared. When she sleeps, she shakes. I’m constantly making sure she’s okay or waking her up. I’m scared sometimes to be with her by myself.” Female, age unknown

* The anxiety themes are categorized into three subgroups: Proband (participant is affected by cardiac channelopathy), Caregiver (participant is affected with children or unaffected with an affected child), Friend/Relative (other participants are unaffected by the disease).

Another anxiety-provoking thought for participants involved the aesthetic effects of ICD placement. Many participants expressed extreme emotional concern over body disfigurement as a result of implantation:

“It was told to [my wife and me] that if she did have a pacemaker this definitely would have saved her. . . . She was very petite and she didn’t want one because the doctor was saying that it would be visible.” Male, age 31

Many participants’ own insecurities with their devices were further reinforced by the thoughts of others:

“I am a small person. [My ICD] is very pronounced. A friend of mine wanted to see it after I had the surgery. I said, ‘Just don’t gasp.’ I showed her and [my friend] was like, ‘ahhhh. . . .’ I told you not to gasp!” Female, age 46

Although many participants were unhappy with the size and appearance of the ICD in their chest, some expressed enthusiasm that devices are becoming smaller over time:

“When did you have the ICD put in?” “Two years ago and then before that it was seven years. They put a whole new one in because the other one was big and stuck out. This [ICD] is nice. You can’t even tell I have it,

other than the scar. The other one was ugly.” Female, age 51

After the ICDs were implanted, many participants were terrified of the potential shocks from the devices. They expressed concern about what it would feel like, what they would be doing should the devices go off, and whether or not help would be nearby:

“Do you worry about the shocks?” “At first I did. You don’t really know what’s gonna set it off. [The doctors] can try to prepare you, but until it happens you have the anxiety, ‘Is it gonna come?’” Female, age 52

“ICDs have killed people misfiring and having an event from your ICD . . . I was feeling so scared and nervous.” Female, age 46

Finally, related to a fear of being shocked, participants expressed anxiety about being alone if their devices fired:

“I called [my mother]. It makes me feel comfortable that somebody knows where I am. Because if I passed out, [my mother] already knows where I am and she could do something about it. I call my mom. I call my sisters. I’ll call anyone.” Female, age 29

Having a family was an extremely influential factor in decid-

ing to have an ICD implanted. Participants were often uninterested in the ICD for themselves; however, they often wanted ICDs to be able to save their lives for the sake of their spouses and children:

"I didn't really want to [have the ICD placed]. . . . My husband made me feel for him I should, for [my kids and grandkids] I should, but for me, I am not afraid of the long QT." Female, age 51

"I do most of the parenting. . . . [W]hat if something happened to me and I had this little 3-year-old?" Female, age 46

Opinions of participants tended to change when they were considering becoming parents. When contemplating starting a family, participants who had never considered having ICDs expressed changes in their perspective:

"I was born this way. I am 34 years old. I am still alive; if [long QT syndrome] takes me out of this world, this is nature unfolding. . . . If I have a child [my views] may

change because then someone else's life is dependent on me." Female, age 34

Another participant expressed similar views after years of not following up with a cardiologist regarding her diagnosis of short QT syndrome:

"I had just had kids and I started thinking, 'If I have short QT, then I want to be able to be around as long as I can for my children.'" Female, age 25

Not only are children extremely important in the decision about ICD implantation, they also often represented a source of anxiety for patients in whom ICDs had been placed. Participants voiced concerns regarding family members, especially children, witnessing a syncopal episode followed by appropriate defibrillation:

"[S]he went on a vacation with the family, and the defibrillator went off twice. . . . All she could remember was seeing her kids scream. . . . [W]hat got her more afraid were the two little guys there watching her go through this." Female, age 30

Table 5 | Complications, Restrictions, and Rumors, and Utility Themes Identified and Described with Examples

Theme	Description	Example
Restrictions & Rumors	MRI Restrictions	<ul style="list-style-type: none"> "R had an MRI, which was his one and only, and now he will never have an MRI [again] because the leads will be in his body forever. I think most people think a seizure is a seizure when it actually could be the heart. It is very rarely reversed." Female, age 58
	Cell Phone Function	<ul style="list-style-type: none"> "My mom has a defibrillator. . . . [S]he's restricted [from] using her cell phone in her left hand. Do you have restrictions like that?" "I do my best to use my right hand . . . but since I'm a lefty, I [try not to] touch the defibrillator." Female, age 38
	External Defibrillator	<ul style="list-style-type: none"> "External defibrillators make people very nervous. Parents of my daughter's friends are not comfortable being alone [with my daughter]. . . . [My daughter's] school started giving us trouble. [The school] was not rejecting kids with asthma inhalers or Epipens. Why are they rejecting a child with an external defibrillator?" Female, age 46
Complications	Multiple Surgeries	<ul style="list-style-type: none"> "[My son will] have a new defibrillator this June. The battery is failing and the epicardial system—he's outgrown it. . . . It starts the whole thing again—anesthesia, what if we lose him? It'll be like that for the rest of his life." Female, age 35
	ICD Storm	<ul style="list-style-type: none"> "I got shocked 15 times in a row, inappropriately! It is a miracle my heart doesn't have scars or damage because of this machine. . . . Getting shocked by [an ICD] is worse than childbirth. I'd rather give birth to a thousand babies, than be shocked one time by [an ICD]." Female, age 30
Utility	Satisfaction	<ul style="list-style-type: none"> "Are you glad you got the defibrillator?" "[I]f it ever saves my life, I'll say 'Yes.' Considering it's never had to shock me yet, I can't say 'Yes' and I can't say 'No.'" Female, age 38
Alternative Therapy	Meditation	<ul style="list-style-type: none"> "I had some friends who do deep meditation [who suggested I meditate] to feel better about my choice [not to have an ICD]. I visualized a ball of white light that will come and wrap around my heart and protect it. . . . I would do that daily. . . . I still do it from time to time . . . [H]ey, it's been eight years [and no events]." Female, age 34

Parents voiced concerns when their children were affected by channelopathies and had defibrillators. Sources of anxiety in this situation included guilt and the question of communicating with children. Caregivers expressed guilt about passing the disease on to their children, and many participants discussed the desire to undergo genetic testing for family-planning purposes. Additionally, parents described feelings of anxiety that events might occur and they would not be present to take care of their children. Explaining to children why they needed ICDs was often difficult. Parents were anxious about affected children running, jumping, and playing competitive sports, and even explaining to their children the reasons for their anxiety was worrisome to many:

“[My daughter] is very active . . . always bouncing. How do I say to her, ‘I’m afraid you might die?’” Female, age 29

Below is an example of an effective communication strategy that one participant used to explain the disease to her daughter:

“[My daughter] doesn’t view [ICD placement] as major surgery. I told her, ‘Your heart takes a little bit longer to restart than most people. [The doctors] want to give you an [ICD] so that if something happens, you’ll be okay until someone can get you to the doctor.’” Female, age 29

Much of the focus on anxiety has been on that felt by patients and parents, but it is important to remember that cardiac channelopathies affect the entire family. Many participants expressed having strong support systems in their families and many of these close relatives and family friends expressed anxiety as well:

“She gets scared her device is gonna go off, so I’ll go over there, but I’m scared. When she sleeps, she shakes. I’m constantly making sure she’s okay or waking her up. I’m scared sometimes to be with her by myself.” Female, age unknown

Receiving ICDs was a life-changing experience for participants. Not only did the participants undergo surgery and live with the worry of arrhythmogenic events and device firing, but they were no longer able to participate in many activities that they had previously. Participants described restrictions on their regular exercise habits, which was emotionally difficult for many. They also talked about being unable to go through metal detectors or obtain MRI scans. The inability to have an MRI scan affected one participant who was misdiagnosed with Brugada syndrome and is now believed to have a seizure disorder:

“R had an MRI, which was his one and only, and now he will never have an MRI [again] because the leads will be in his body forever. I think most people think a seizure is a seizure when it actually could be the heart. It is very rarely reversed.” Female, age 58

Participants also described a notion that others do not and cannot fully understand the implications of living with ICDs. Participants’ quality of life changed, and many individuals had to modify their lifestyles and plan to be close to medical facilities at all times in the event that arrhythmias requiring ICD firing should occur.

Some participants expressed beliefs concerning ICDs that are not necessarily true. One patient often expressed fear that using a cell phone would prevent his device from working properly:

“My mom has a defibrillator. . . . [S]he’s restricted [from] using her cell phone in her left hand. Do you have restrictions like that?” “I do my best to use my right hand . . . but since I’m a lefty, I [try not to] touch the defibrillator.” Female, age 38

Restrictions associated with external defibrillators were also expressed. External defibrillators are widely prescribed for patients with cardiac channelopathies. They provide a means for quick defibrillation during sudden cardiac arrhythmias, and often serve to empower parents and family members close to patients who may otherwise feel powerless to help those afflicted. However, one participant expressed restrictions regarding play dates and school attendance because of her daughter’s external defibrillator:

“External defibrillators make people very nervous. Parents of my daughter’s friends are not comfortable being alone [with my daughter]. . . . [My daughter’s] school started giving us trouble. [The school] was not rejecting kids with asthma inhalers or Epipens. Why are they rejecting a child with an external defibrillator?” Female, age 46

Many participants mentioned ICDs in the context of complications they experienced secondary to ICD implantation. Complications described included a serious infection that required device explantation, and a fractured device lead shortly after initial surgical implantation requiring explantation with a second device implantation. Many participants described problems with battery life and the need for multiple surgeries every five to seven years. Participants expressed concern over recurrent surgeries, and regardless of the number of procedures required, they commented that it never got easier:

“[My son will] have a new defibrillator this June. The battery is failing and the epicardial system—he’s outgrown it. . . . It starts the whole thing again—anesthesia, what if we lose him? It’ll be like that for the rest of his life.” Female, age 35

One participant suffered from frequent inappropriate shocks and experienced an “ICD storm” with perpetuating, continuous shocks secondary to an initial inappropriate device firing:

"I got shocked 15 times in a row, inappropriately! It is a miracle my heart doesn't have scars or damage because of this machine. . . . Getting shocked by [an ICD] is worse than childbirth. I'd rather give birth to a thousand babies, than be shocked one time by [an ICD]." Female, age 30

Because of the lifestyle restrictions and complications associated with ICD placement, many participants reported dissatisfaction with the devices. Most commonly their disappointment was with device utility, meaning that during the time when many patients had their devices implanted, they never required an appropriate defibrillation shock. Although this could be considered positive, given the invasiveness of the initial and subsequent procedures and the implications for quality of life, patients were at times ambivalent about their decision to have ICDs implanted:

"Are you glad you got the defibrillator?" "[I]f it ever saves my life, I'll say 'Yes.' Considering it's never had to shock me yet, I can't say 'Yes' and I can't say 'No.'" Female, age 38

One participant found meditation extremely helpful in reducing the anxiety surrounding her heart condition, especially given her decision not to undergo device implantation.

"I had some friends who do deep meditation [who suggested I meditate] to feel better about my choice [not to have an ICD]. I visualized a ball of white light that will come and wrap around my heart and protect it. . . . I would do that daily. . . . I still do it from time to time. . . . [H]ey, it's been eight years [and no events]." Female, age 34

CONCLUSION

Participants in this study reported recurrent issues when discussing ICDs, including comprehension and physician-patient communication, anxiety, complications, restrictions and fallacies, utility, and alternative therapy. These results were similar to many of the findings in the current literature examining the quality-of-life implications of ICD implantation (Eckert & Jones, 2002; Kamphuis, de Leeuw, Derksen, Hauer, & Winnubst, 2003; Syska et al., 2010; Wójcicka, Lewandowski, Smolis-Bak, & Szwed, 2008).

Our findings include many that are consistent with those of previous studies. A qualitative study by Anderson and colleagues focusing on the impact of living with a diagnosis of LQTS identified several important themes, including concern for family members, limitations in their daily lives, and a lack of understanding within a medical community fraught with uncertainty, misinformation, and inaccurate advice regarding clinical management (Andersen, Øyen, Bjorvatn, & Gjengedal, 2008).

The psychological ramifications of living with ICDs have been studied, representing the heart-disease population at large. Patients with severe heart disease who require ICD

implantation often suffer from co-morbid depression. In patients affected by co-morbid depression at implantation, depression persists in 72% of patients post-implantation. Patients with clinical depression and ICDs are at increased risk of shocks (36%) compared with nondepressed patients (9%) (Suzuki et al., 2010). In a longitudinal study following patients with ICDs over four years, mental-health scores and overall psychological health scores improved significantly, while overall quality-of-life scores remained stable after device implantation (Carroll & Hamilton, 2008). Two studies identified younger age at implantation as a significant risk factor for the development of clinical depression and anxiety as well as worsening quality of life (Friedmann et al., 2006; Thomas et al., 2006). A recent study by Probst and colleagues found that patients diagnosed with Brugada syndrome reported that ICDs have a negative social impact on their lives (Probst et al., 2011).

One study examining physicians' views of their patients' quality of life post-implantation found that 47% of patients reported the same quality of life and 15% reported worsening quality of life with significant emotional and relationship strain. Furthermore, physicians reported discomfort in providing emotional and psychological support to their ICD patients, indicating the need for improved communication and encouragement from providers caring for patients with ICDs (Sears et al., 2000). In a randomized trial evaluating the use of ICD patient education and cognitive behavioral therapy, patients were less anxious, had lower cortisol levels, and reported increased acceptance of their ICDs after the intervention, further supporting the need for improved physician-patient communication in patients with ICDs (Sears et al., 2007).

Our study identified communication breakdown as a major cause of distress among patients receiving ICDs. Communication issues were not addressed in the published literature. Patients expressed their desire to have the opportunity to discuss ICDs prior to implantation, and in cases where this did not occur, more complications and dissatisfaction resulted. If immediate implantation was required, family members, especially caregivers, desired that they be informed about the reasons for device implantation and allowed to voice their concerns to ease anxiety, especially during emergency situations. This suggests that the need for an ICD, the mechanism of action of the ICD, and all risks and benefits of the procedure should be addressed prior to implantation, if possible. It is important not only to be effective communicators, but to be effective listeners as well. Although some patients were uneducated regarding their illness, others were extremely well informed. Patients and families were capable of comprehending these illnesses when provided with the appropriate tools, and their wishes should be respected as long as the patients or the healthcare proxies provided appropriate justification for decisions.

Many participants were ambivalent about their ICDs. Although the ICDs had been placed to protect them

Table 6 | Summary of Suggestions

Suggestions	Description
Promote Communication	<ul style="list-style-type: none"> Providers should encourage their patients to speak with cardiologists and geneticists or genetic counselors to further understand their disease. Providers should use open communication strategies to elicit concerns from patients with cardiac channelopathies and ICDs. Providers should elicit common misconceptions from patients, and empower patients with knowledge addressing these fallacies. Providers should encourage communication concerning family planning when appropriate. Providers should encourage open communication among family and friends. A strong support system is important for patients with cardiac channelopathies.
Encourage Anxiety-Alleviating Strategies	<ul style="list-style-type: none"> Patients may find deep meditation and other strategies helpful in controlling their anxiety. These strategies may be used as adjunct therapies in conjunction with current treatment guidelines.
Provide Information on ICD Support Groups	<ul style="list-style-type: none"> Support groups will likely ease the potential sense of isolation, and may provide insight and offer strategies to combat the anxiety-provoking factors concerning the patients' disease and their ICDs. Support groups are effective tools for parents and other family members and friends who are affected by the patients' disease as well. Examples of support groups: <ul style="list-style-type: none"> The Zapper: http://www.zapliflife.org The Pacemaker Club: http://www.pacemakerclub.com/public/jpage/1/p/Home/content.do Familion: http://www.familion.com/familion/patients/resources/resources.cfm Sudden Arrhythmia Death Syndromes: www.sads.org Cardiac Arrhythmias Research and Education Foundation: www.longqt.org Ramon Brugada Senior Foundation: www.brugada.org The National SIDS/Infant Death Resource Center: www.sidscenter.org National Society of Genetic Counselors: www.nsgc.org Heart Rhythm Society: www.HRSonline.org American Heart Association: www.americanheart.org Hypertrophic Cardiomyopathy Association: http://www.4hcm.org/ Children's Cardiomyopathy Foundation: www.childrenscardiomyopathy.org Hannah Wernke Memorial Foundation: http://www.hannahwernkememorialfoundation.com/

against fatal arrhythmias, many of the devices had never fired. This frustrated many participants, and a similar result was reported in a study by Sherrid and Daubert (2008); discussing, prior to implementation, the possibility that the ICDs would never fire might help ease patients' negative feelings long after undergoing implantation. Much of the literature reports contentment with ICDs regardless of firing; however, Sherrid and Daubert's study, like the present study, examined ICD perceptions in a younger patient population (Kamphuis et al., 2004; Sherrid & Daubert, 2008; Wójcicka et al., 2008). It is possible that patients who are younger and suffering from cardiac channelopathies with minimal symptoms have different outlooks on their health status and the utility of device placement when compared to older patients suffering from congestive heart failure and its associated symptoms. More research is needed in this area to confirm this assertion.

It is important, when providing care to patients with ICDs, to identify those patients who are at increased risk of developing anxiety or depression. Thomas and colleagues identified patients with ICDs and the following characteristics to be at increased risk of developing psychiatric disorders: younger patients, patients who had experienced shocks in the past, and patients who reported current psychological

distress or a prior history of psychological distress (Thomas et al., 2006). Since the patient population affected by hereditary cardiac channelopathies is typically younger at age of implantation when compared to the total population of patients with ICDs, this population is inherently at higher risk for developing anxiety, depression, or both. Therefore, screening and treatment for anxiety and depression should be addressed in the care of patients with ICDs.

It is not clear how best to prevent the development of substantial mood disorders in patients and promote positive communication and outlooks. In a randomized clinical trial, patients with ICDs were provided with ICD education and cognitive behavioral therapy for their devices. These patients had reduced physiological levels of cortisol, less psychological distress, and improvements in quality of life (Sears et al., 2000; Sears et al., 2007). This study, like others, identified problem-focused, optimistic coping strategies as the most useful in patients with chronic diseases and patients with ICDs (Flemme, Johansson, & Strömberg, 2012; Hallas, Burke, White, & Connelly, 2010; Kristofferzon, Löfmark, & Carlsson, 2005; Lindqvist, Carlsson, & Sjöden, 2004). In addition, holistic practices may be of use in this patient population for easing stress, as exemplified by the meditation exercise described by one participant in this

study. But although meditation exercises may reduce the anxiety surrounding a patient's diagnosis with a familial channelopathy, this should not be interpreted as a reduction in the severity of the patient's disease or in the risk of developing an arrhythmia, possibly fatal.

Given the small sample size and the subanalysis of a larger study, the results of this study are difficult to generalize. However, the results reflect similar findings in the current literature and are suggestive of issues surrounding ICDs that more patients may experience. It is also possible that participants who offered opinions regarding their ICDs more often had negative experiences regarding their own or a family member's ICD. Only one participant included in this subanalysis of the study was less than 21 years of age, making the generalizability to children of this study's findings difficult; however, given the concerns of the parents in this study and this one child, it is likely that other families experience similar concerns. The small sample size and number of participants from a specific geographical region, as well as the large representation of female participants compared with male participants, limit the generalizability of these findings. Additionally, self-reporting is prone to reporter bias. However, the themes identified in this study likely represent concepts and concerns shared by many other patients with ICDs, and should be useful in aiding healthcare providers in their discussions with patients who have ICDs or are contemplating ICD implantation. We offer a final set of suggestions in an effort to improve patient clarity concerning cardiogenetic disease (Table 6).

Corresponding Author

Siobhan M. Dolan, MD, MPH (siobhanmdolan@yahoo.com), 1300 Morris Park Avenue, Block Building, Room 634, Bronx, NY 10461.

Conflict of Interest Disclosure

The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. No conflicts were noted.

Author Contributions

JL carried out the data analysis/interpretation in this study, drafted the article, and performed a critical revision of the article, including statistical analysis. NH was involved in the concept and design of the article, collected the data, and performed a critical revision of the article. MS was involved in the concept and design of the article, performed data collection, and performed a critical revision of the article. TM was involved in the concept and design of the article, performed a critical revision, and approved the manuscript. RM participated in the concept and design of this article, gave a critical revision, and approved the manuscript. CW contributed to the concept and design of the article and data collection, provided a critical revision, and approved the manuscript. SD was involved in the concept and design of the article, provided a critical revision, and approved the manuscript.

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Abbreviations

BS = Brugada syndrome; CPVT = catecholaminergic polymorphic ventricular tachycardia; ICD = internal cardioverter-defibrillator; LQTS = long QT syndrome; SCD = sudden cardiac death; SIDS = sudden infant death syndrome; SQTS = short QT syndrome; SUDC = sudden unexplained death in childhood; SUDS = sudden unexplained death syndrome

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