

# Adolescents with Implantable Cardioverter Defibrillators: A Patient and Parent Perspective

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**Background:** An implantable cardioverter defibrillator (ICD) is a device used in the treatment of individuals with life-threatening cardiac conditions. These include genetic disorders such as long QT syndrome, hypertrophic cardiomyopathy, and Brugada syndrome, all of which have the propensity to cause sudden cardiac death. Adults with ICDs consistently report elevated levels of anxiety and depression, as well as negative lifestyle changes associated with the device. Compared to older ICD recipients, young patients face decades of life with the device and the long-term impact and implications are important to consider. This research explores the experiences of adolescents living with an ICD. Parents of these adolescents were also included to explore the impact on them as the primary caregivers.

**Methods:** A qualitative approach was chosen to explore the lived experience; semistructured interviews with six adolescents and six parents were conducted from which a number of key themes emerged.

**Results:** The experiences described by participants included the restrictions adolescents face, the ICD shock experience, and ongoing challenges post-ICD implantation. However, both adolescents and parents were able to adjust to life after receiving an ICD and described several benefits associated with having the device. Findings also emerged relating to communication between health professionals and adolescents, and the limitations adolescents impose on themselves post-ICD implantation.

**Conclusion:** These findings have important implications for clinical practice and may help guide medical management for adolescents with ICDs and their families. (PACE 2011;1–11)

## **implantable cardioverter defibrillators, adolescent, sudden cardiac death, qualitative research**

### **Introduction**

An implantable cardioverter defibrillator (ICD) is used in the treatment of people with life-threatening cardiac conditions. The medical benefits of ICDs are well established, with the device significantly extending life expectancy.<sup>1</sup> Research is now focusing on the psychosocial effects of ICDs and the impact on quality of life related to ICD therapy. Patients with an ICD consistently report elevated levels of anxiety and depression, as well as negative lifestyle changes associated with the device.<sup>2,3</sup> However, almost all research has focused on the adult population as

until recently the use of ICDs in young patients was rare; currently less than 1% of ICD patients are under 21 years of age.<sup>4</sup>

As there are little data available about young people (under 18 years) with ICDs, the psychosocial impact of having the device as an adolescent is largely unknown. It would be inappropriate to extrapolate the results from research on older patients to younger recipients. The reasons that adolescents receive ICDs can be different from the reasons adults receive ICDs. For example, in younger patients, ICDs are more often used as a preventative measure of sudden death in genetic diseases.<sup>5</sup> There can also be more complications associated with the device in younger populations, which may result in more surgery, increased time spent in the hospital, and increased risk of infection at the wound site.<sup>6</sup> Adolescence is also a time of potential conflict, confusion, and stress marked by physical, emotional, and psychosocial changes.<sup>7</sup> A potentially life-threatening diagnosis and the challenge of coping with an ICD may exacerbate this already difficult period in adolescents' lives and may challenge young people in establishing

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identity, intimacy, and autonomy. Young ICD patients are a “unique subset” who face challenges specific to their age and stage of development.<sup>8</sup> By identifying these challenges faced by adolescents, a greater understanding of their experiences can be developed, which will in turn inform clinical practice and encourage further research.

Recent in-depth theorizing of the most likely and significant psychosocial issues adolescents with ICDs may face included fear of being shocked by the device, activity restrictions, and feeling different from peers. The current paper takes a crucial step in beginning to validate some of these theoretical hypotheses empirically.<sup>9</sup>

### Background

Despite the limited number of studies in this adolescent age group, a trend seems to be emerging that quality of life and psychosocial adjustment may also be compromised in young ICD patients. Most research has been quantitative using clinical measures or self-report questionnaires with only a small number of studies using interviews to explore opinions and attitudes related to psychosocial issues of ICD implantation. Poor psychosocial adjustment measured by increased levels of anxiety and depression has been shown in younger ICD recipients.<sup>8,10</sup> Perceived decrease in quality of life has been shown in both adolescent ICD patients<sup>5</sup> and their parents.<sup>11</sup>

A recent study of 14 adolescents with ICDs used in-depth interviews to explore their experiences of living with the device.<sup>7</sup> The overall theme that emerged from this study was that adolescents felt “almost normal,” with the concept of normality and perceptions of their previous existence altered by ICD implantation so that life was “. . . not quite ever the same again” (p. 144). Although the adolescents were conscious of the challenges both the device and their diagnoses presented, learning to acknowledge their strengths, minimize their limitations, and/or recognize the benefit of the device assisted them in moving forward with their lives.

The current study sought to build on this previous research concerning young people and ICDs to document and explore in detail their experiences of living with the device. The study also aimed to explore the experiences of parents of these adolescents to better understand the impact of receiving an ICD on the primary caregiver. Qualitative methods were chosen due to the limited knowledge that currently exists about young people’s experiences of ICDs. Through in-depth study of individual experiences, phenomenology aims to identify both the meaning and common features of a particular experience or event, while privileging the personal, subjective experience.<sup>12</sup>

Thus, the use of qualitative methods in the current study facilitated understanding of the impact of the ICD on adolescents and their parents by providing an opportunity for these individuals to express their personal accounts.

## Methodology

### Participants

Participants were adolescent patients of the Royal Children’s Hospital, Melbourne, Australia, aged between 12 and 17 years, with a presumed or diagnosed cardiac genetic condition. All participants had an ICD. Diagnoses were made by a Pediatric Cardiologist using accepted criteria<sup>13–15</sup> and were based on cardiac investigations and participants’ clinical history. One parent of each adolescent participant was also invited to participate in the study. Potential participants were excluded if they were not fluent in English, as interviews could only be conducted in English, and/or if they had neurological impairments that precluded them from being able to engage in an interview. Ethics approval for this study was obtained from the Royal Children’s Hospital Human Research Ethics Committee.

A purposive sample of potential participants was identified through a computer database used at the Royal Children’s Hospital cardiology department. The registered nurse and cardiac technician involved in the care of all ICD patients at the hospital created a list of potential participants using the criteria above.

As cardiac genetic conditions are rare, and only a small subset of clinically diagnosed individuals requires implantation of an ICD as part of their treatment, there were a limited number of individuals who met inclusion criteria. Nine potential adolescent participants were identified; of these, six agreed to participate. One parent of each of the six adolescent participants also agreed to be interviewed for the study. The demographic details of these participants are presented in Table I. To protect the privacy of participants, pseudonyms are used throughout.

### Recruitment

Recruitment of participants occurred in two stages. During stage one, a member of the treating team contacted the parent of each eligible adolescent, alerting them to the study and asking them if they would be interested in speaking to the study coordinator. In the second stage of recruitment, the study coordinator contacted interested participants to provide more detail about the study and the nature of participation. Participant information and consent forms were

**Table I.**  
Demographic Characteristic of Participants

| Pseudonym of Adolescent Participant | Gender | Age at Interview | Indication for ICD   | Cardiac Arrest | Primary or Secondary Prevention | Duration with ICD at Time of Interview | ICD Replacement | No. of Shocks*         | Pseudonym of Parent of Participant |
|-------------------------------------|--------|------------------|--|----------------|---------------------------------|--|-----------------|------------------------|------------------------------------|
| Sophia                              | Female | 15               | Catecholaminergic polymorphic ventricular tachycardia (CPVT)   | Yes            | Secondary                       | 5 years 3 months                       | No              | 2 (both appropriate)   | David                              |
| Lauren                              | Female | 16               | Possible cardiomyopathy with ventricular tachycardia (VT)      | No             | Primary                         | 4 years 6 months                       | No              | 0                      | Maria                              |
| Dean                                | Male   | 17               | Brugada syndrome   | No             | Primary                         | 3 years 4 months                       | No              | 1 (for atrial flutter) | Sue                                |
| Jake                                | Male   | 17               | Possible long QT syndrome (LQTS)                               | No             | Primary                         | 1 year 11 months                       | No              | 0                      | Kathy                              |
| Ben                                 | Male   | 17               | Left ventricular noncompaction/dilated cardiomyopathy (DCM)    | No             | Primary                         | 10 months                              | No              | 0                      | Leanne                             |
| Matilda                             | Female | 15               | Hypertrophic cardiomyopathy (HCM) and Wolff Parkinson syndrome | No             | Primary                         | 1 year 7 months                        | No              | 0                      | Jenny                              |

\*referring to number of shocks delivered by the ICD

sent to the adolescent and his or her parent. Interviews were then organized at a time that was convenient for the participants, usually to coincide with their next appointment at the hospital, or a telephone interview was arranged if participants were unable to attend the hospital.

### Data Collection

All interviews were conducted by BR between June and September 2009. The interview outline for adolescents focused on their personal experiences of living with an ICD and the impact this had on different domains of their life. Questions included, *What was it like for you when you first got your ICD? How has your life changed after getting your ICD?* and *What is it like talking to your friends about living with an ICD?* A slightly different focus was adopted in interviewing the parents of adolescents; broad themes included their opinions about the impact on their child of living with an ICD, as well as their own personal experiences of their child's diagnosis and ICD implantation. Questions included, *What is it like being a parent of a child living with this condition, and the ICD? What impact has the ICD had on your child and their life?* and *What impact has your child's ICD had on you?* The interview outline was piloted prior to the participant interviews with a clinical employee of the cardiology department.

Parent and adolescent interviews were conducted separately to maintain the privacy of all participants. Of the interviews conducted, eight were completed face-to-face, and four were conducted by telephone as per participant preference. All interviews were digitally recorded and transcribed verbatim.

### Data Analysis

Thematic analysis was chosen as the technique for analyzing the transcripts. Thematic analysis is a method for identifying, analyzing, and describing patterns or themes within the data.<sup>16</sup> It produces thematic descriptions that provide insight into the meaning of the lived experience.<sup>12</sup>

The process of thematic analysis closely followed analysis phases that have been previously described.<sup>16,17</sup> The first stage involved reviewing the transcripts, noting down emerging ideas related to particular phrases, words, and descriptions of the participant's experiences. The next stage involved generating initial codes in a systematic manner for the entire data set, highlighting features that were interesting or important. Similar but separate codes were then collapsed and refined to create potential themes. In the final step of the analysis, process theme names were refined and organized into a final theme list to reveal the overall story of the data.

To maximize rigor in this study, a number of strategies were employed. First, the audiotapes of the first two interviews were reviewed for content and structure by three members of the research team, experienced and skilled in qualitative research. Summarizing and rephrasing by BR throughout the interviews provided clarification and ensured an accurate understanding was obtained of the participants' views and experiences. Transcripts were also coded separately by three members of the research team; any inconsistencies between coders were discussed until consensus was reached.

### Results

Eight key themes emerged from the data. These are now described in detail. The codes at the end of each quote refer to the participants' pseudonym, their age at the time of interview, and their diagnosis.

#### Restrictions

Being physically restricted was a theme that emerged during the interviews with adolescents. Almost every adolescent had the experience of being previously active and then being severely restricted in the amount and type of activities they could participate in. This occurred as a result of a cardiac event and the subsequent implantation of the ICD. Participants often described their negative reactions to the physical restrictions they now faced.

*"I mean when I was younger and I was told that I couldn't do sport that really affected me because I was really into sport and you know every kid runs around and plays tiggy and that, so I was like bawling my eyes out when he told me and I hated the doctor"* (Matilda, 15, HCM)

Parents also described the physical restrictions their children faced as a result of having an ICD. Several parents identified and acknowledged the significant impact that such restrictions have had on their child's life.

*"... you know you see her cry and just say to me, 'My life is over because this is one thing I like doing and it's got taken away from me', and I just felt like I wanted her to play sport because it was something she enjoyed doing"* (Maria)

#### (Not) Being Normal

The majority of adolescents described their lives post-ICD implantation as "not normal."

The previous routines of everyday life were significantly disrupted by the ICD itself and the ongoing medical management, as well as the restrictions that they faced as a result of the ICD.

*“It’s not a normal life but it’s hard to explain”*  
(Sophia, 15, CPVT)

Often the concept of “being normal” was drawn from comparing what the adolescent participants had been able to do before their ICD and what they were unable to do now. Peer comparison also contributed to adolescent perceptions of normality.

*“I mean when I was young it probably affected me a bit more because I was sort of like not normal, you know? Most kids could do other stuff and I couldn’t”* (Matilda, 15, HCM)

*“... that’s probably the biggest impact, is just stuff that people take for granted that they can do or just it’s their right to do, I’m unable to do”* (Jake, 17, LQTS)

In contrast to their children, parents often spoke of the normality of their child’s life and their efforts to “be normal.” Some participants also described the importance of their child being as normal as possible for them as parents.

*“I’d like him to sell the motorbike... but you can’t say, ‘You can’t be a normal teenager’ ’cos you want him to be as normal”* (Sue)

### Professional Communication

The theme of professional communication emerged from participants’ descriptions of their interactions with health professionals. Adolescents described a range of explanations that had been given to them about the ICD. Some participants felt the information and the way in which it was communicated could have been improved.

*“He (doctor) told me which, what this did and what this did and he used the simile of cars which was terrible because I don’t exactly like cars”* (Ben, 17, DCM)

Communication between medical staff, particularly the doctors, was a significant theme that also emerged from the parent interviews. The important impact of the words and advice of the clinicians featured strongly in participants’

stories with parents often recalling the exact words used by the doctor. For some parents, a lack of communication between the medical professionals and themselves or their children was distressing.

*“... no one sort of says anything”* (David)

*“... everything through his whole life he’s just been told things. It’s only that ((doctor)) said it would be better not to tell him straight up”* (Sue)

Parents felt it was important that there was open communication not only between parents and clinicians, but also the adolescents and their doctors.

*“And maybe just talk to the kids, even if you simplify it that um this is going and this is what it does and it needs to happen... No matter how old they are, it’s still their body that it’s going into”* (Sue)

### Adjusting to Life with an ICD

Coping with life post-ICD implantation was a common theme described by the participants. Although life would never be quite the same as before the ICD, the adolescents felt that they were able to adjust to the ICD itself and the impact it has had on their lives.

*“Yeah, it’s just like another body part”*  
(Sophia, 15, CPVT)

*“... it’s manageable and [pause] you can live with it and you can deal to live with (it)”*  
(Dean, 17, Brugada)

Part of the adolescents’ attempts to adjust to the ICD entailed thinking about their ICD in a positive way. By trying to focus on what they were still able to do and/or the life-saving benefit of the ICD, they were able to move on and continue with their lives.

*“Yeah, probably not thinking about it as in a negative thing all that much ’cos I haven’t and I’m not too worried about it... knowing that it’s there to prevent something bad going wrong with you and knowing it’s there to help you and if it wasn’t there that something bad could probably go wrong because all ICDs are there to help not to [pause] hinder the person”* (Dean, 17, Brugada)

Coping successfully with the ICD emerged as a broad theme area from parent interviews. A strong sense of admiration was clearly evident as parents described the ability of their children to adjust to the ICD in a positive way. Similarly to their children, parents identified the importance of carrying on with life as much as possible and finding alternatives to help with this.

*“He hasn’t allowed it to let him, to take him down or anything like that. He has coped with it a lot better than I think some other kids would have done”* (Kathy)

*“...but you know at the end of the day [pause] you can’t sit at home and not do anything”* (Jenny)

### Benefits of the ICD

While acknowledging the significant impact the ICD has had on their lives, the adolescent participants were able to describe the advantages of having the device.

*“I’m pretty sure than an advantage would be my heart would not stop if the device is working, which is a pretty good advantage I’m thinking”* (Ben, 17, DCM)

For some adolescents, their ICD was there “just in case,” to be used in the event of a dangerous heart rhythm. The knowledge that it was a life-saving device provided reassurance and peace of mind for the adolescents. Having the device even provided one participant with a greater sense of independence, and another participant described the advantage of the device as also providing reassurance for his parents now and in the future.

*“It was more of just a thing for Mum and Dad so that they could rest easy – not just for my childhood but when I’m older in life and maybe there won’t be somebody there always to look after me and whatever, that, that’s going to make sure that I’m alright”* (Jake, 17, LQTS)

*“Yeah, I want some space from them. I don’t want them to have to follow me round and make sure I’m alright. It’s sort of like my security blanket having this defibrillator”* (Matilda, 15, HCM)

For the parent participants, talking about the advantages of their child having an ICD emerged consistently from the interviews. One benefit of

the ICD parents described was the reassurance it provided them knowing that the device was there to save their child if he/she experienced a dangerous cardiac arrhythmia.

*“It’s obviously a good thing. It’s keeping my daughter alive”* (David)

*“It’s laid my mind at rest. Like I said, when he didn’t have it, if he stayed home on his own I was on the phone to him every five minutes... I was always on the phone, checking up on him”* (Kathy)

For one parent, the ICD provided not only peace of mind for herself, but also greater independence for her child.

*“He was feeling really closed in because we were always on his back saying, are you alright are you alright. It was a constant reminder for him that he wasn’t well. Whereas, this has sort of given us all peace of mind, really”* (Kathy)

### Ongoing Challenges

A common theme that emerged from the interviews with adolescents entailed the challenges they continued to face after getting their ICDs. Ongoing appointments and medical checkups were a constant disruption for some adolescents. The continued disruption to school life for appointments was also a significant challenge, particularly given that three of the participants were in their last year of high school and soon to be sitting their final exams.

*“I suppose it’s now the check-ups, just like the constant having to come here”* (Sophia, 15, CPVT)

*“I dunno it’s been difficult because I can’t always have to keep that in the back of my mind whenever I’m doing something because I can’t always miss so much time... you can always [pause] like get the coursework but [pause] you can’t get what they’ve said in class”* (Dean, 17, Brugada)

Issues with the ICD after implantation often presented an ongoing challenge for participants; for example, one participant required multiple surgeries for lead repositioning. Another ongoing challenge these adolescents face for the rest of their lives is battery or device replacement, which requires more surgery and time spent in hospital.

*“... after that they put the defibrillator and it didn't work the first and second time... so I had three different operations” (Lauren, 16, VT)*

*“... my ICD cords are bung... Apparently in America some of them have been shocking for no reason because of these cords so my doctor has to keep an eye on it. Keep me on my toes!” (Dean, 17, Brugada)*

Device or battery replacement was the main concern of parents when discussing the continuing challenges faced by their children after ICD implantation.

*“It worries me that every five years it's got to be replaced” (David)*

*“... yeah, that's another thing I'm guessing soon she'll need the battery replaced [pause] that's awful that she has to go getting it [pause] that done again but yeah” (Maria)*

### The ICD Shock Experience

Of the six adolescent participants, two had actually experienced the ICD shock therapy. For the participants who never had an ICD shock, there was a common fear of getting a shock and concern that it was going to be a painful experience.

*“... when my heart beats faster all I'm thinking is I don't want this defibrillator to shock me, that's the worst thing that could happen” (Lauren, 16, VT)*

*“... ((doctor)) told me it was like being kicked in the chest by a horse. Don't want to feel that!” (Jake, 17, LQTS)*

For two participants who had received an ICD shock, both described the anticipated shock as worse than the actual shock experience.

*“I thought it would be worse than what I thought it was. Yeah, it wasn't that bad” (Sophia, 15, CPVT)*

For one participant, it was important to remember that although the shock experience may be painful, it is bearable.

*“... if you think about it, it's just like a shock, like you're not going to die from that one shock. I know it's painful and everything and that sounds a bit weak but it's [pause] it's*

*just a shock like I'll always recover from that shock so it's alright” (Matilda, 15, HCM)*

Feelings of concern, fear, and anxiety surrounding the ICD shock were commonly described by parents, but some parents emphasized the necessary nature of the ICD shock as a potentially life-saving event.

*“If it's restarting his heart and kicking his heart into rhythm, it's fine, it's fine” (Sue)*

### Holding Back

Describing their experiences of life after the ICD implantation, the adolescent participants commonly identified a sense of “holding themselves back.” Adolescents noticed that they were now more cautious and described a “limit” that they could reach, but would not exceed.

*“... whether it was a physical thing or just a mental thing, but I was like holding myself back, trying not to overdo it” (Jake, 17, LQTS)*

*“... that I am limited more um [pause] that I have to be careful what I do, that I'm not as able as I was beforehand but am a lot more aware now” (Dean, 17, Brugada)*

### Discussion

This qualitative exploration of the experiences of young people with ICDs, and their parents, supports existing findings in the literature but also identifies several important experiences not previously reported.

A unique finding from the current study was the differences that exist between parental perceptions and adolescent perceptions. Parents felt that their children were “normal,” whereas adolescents described being “not normal” or “different.” As one parent said, “Well, he is normal but he's just got this thing to help him along” (Sue). The theme of not being normal was also reflected in a previous study of adolescents with ICDs.<sup>7</sup> In this study, the adolescent participants described how once they received an ICD, life was changed irreversibly: “... the concept of normal disappeared when ICD placement was required” (p. 144). The adolescents attributed their feelings of being not quite normal due to limitations such as physical restrictions and concern about the appearance of the device.<sup>7</sup> In the current study, adolescents perceived physical and other restrictions as not only limiting them in what they used to do, but also preventing them from doing what their peers and other “normal” people were

currently able to do. It was this comparison to life before their ICD and the life of their peers currently that created the feeling of being different. Yet, parents did not describe their children in the same way, preferring to describe their children as normal despite the ICD.

Also, unique to this study was the sense of greater independence that the ICD provided to two adolescent participants. Matilda (adolescent) had to carry an external defibrillator with her for many years before receiving an ICD. This external device had to be with her at all times, and she described her ICD as a “security blanket” that provided her with a greater sense of freedom and independence. Similarly, Kathy (parent) noted the positive impact that having the ICD had on her son Jake’s independence; she now felt comfortable giving him much more space and freedom. This is in contrast to the loss of independence as described by adults with ICDs, which may be due to the restrictions the device imposes on driving and work life that in fact remove independence in adults with ICDs.<sup>18,19</sup>

Literature on communication between adolescents with chronic illness and their doctors has shown that the communication skills of the physician can affect how well information is exchanged and understood.<sup>20</sup> Currently, no previous research has focused on professional communication with adolescents with ICDs. In his interview, Ben (adolescent) described how his doctor explained the difference between an ICD and a pacemaker by using different types of cars as an analogy, which in Ben’s opinion “was terrible.” Being well informed of the diagnosis and medical condition is vital as understanding can enhance psychological wellbeing and adherence.<sup>21</sup> Clearly, *how* information is communicated as well as the type of information that is communicated is important for adolescents. Further, work may be needed concerning how best to communicate with adolescent patients in a developmentally appropriate way.

For the adolescent participants, physical restrictions were seen as the most significant aspect of living with an ICD and the most challenging to adjust to. Unlike the restrictions in this sample of adolescents, physical restrictions in adults with ICDs are often self-imposed.<sup>19</sup> Adult ICD patients are reluctant to resume previous activities such as routine exercise for fear of triggering an ICD shock, which therefore leads to a self-imposed restricted lifestyle.<sup>18</sup> Reduced physical functioning has been described as a factor associated with increased psychological distress in adults with an ICD.<sup>22</sup> Lower levels of physical functioning have also been associated with a reduced quality of life in children with

ICDs.<sup>5</sup> Evidence from these studies suggests it is important for adolescents to maintain their involvement in recreational activities as much as possible, particularly as quality of life is strongly influenced by the ability of the ICD patient to resume a “pre-ICD lifestyle.”<sup>18</sup>

The main benefit associated with the ICD was the reassurance and peace of mind that it provided for the adolescents as well as their parents, mostly through the knowledge that it was a protective, life-saving device. This sense of relief and reassurance was reflected in a study of children with ICDs for long QT syndrome, where both the young people and their parents felt that the sense of security provided by the ICD far outweighed the negative experiences.<sup>23</sup> Adults with ICDs have described relief and a sense of gratitude that “. . . the device was keeping them alive.”<sup>19</sup> Adolescent ICD patients have also described the security and “freedom from danger” as an important benefit of having the device.<sup>7</sup>

Concern and anxiety surrounding the expectation and experience of an ICD shock is well documented.<sup>7,19</sup> Although the parents in this study reflected this anxiety, some parents acknowledged that the shock could potentially be a life-saving event. A similar attitude has previously been described; four children who received inappropriate shocks felt the discomfort of the experience was outweighed by the sense of security provided by the ICD, and none of the participants regretted the decision to have the device implanted based on the discomfort associated with the shocks.<sup>23</sup> Framing the ICD shock in this positive way was helpful for these individuals, and may be helpful for other adolescents and their parents to minimize the anxiety around the expectation of the shock experience.

Although parents and adolescents described benefits associated with the ICD, the challenges that continued after implantation were also significant in their lived experiences. Adolescents faced disruptions with ongoing medical appointments and both parents and adolescents were concerned about the need for the ICD to be replaced regularly; for the participants, this meant more surgery, risks, and recovery. The knowledge that this would be a continuing part of life had an important impact on adolescents and parents, who described ICD replacement as an “awful,” stressful event. The continuing challenges post-implantation have been articulated in past research. In a study of the parental perceptions of long QT syndrome, parents felt ICD implantation was a difficult decision to make because of this need for long-term maintenance.<sup>24</sup> Concern for the future in the

**Table II.**  
Key Themes and Their Clinical Implications

| Key Theme                  | Implications   |
|----------------------------|--|
| Restrictions               | Physical restrictions were described as the most challenging aspect of living with an ICD. As reduced physical functioning has been associated with a lower quality of life, it is important that alternative activities are encouraged and supported for adolescent wellbeing.  |
| Not being normal           | Adolescents described themselves as “not quite normal” after receiving an ICD. As adolescents often want to conform to and be accepted by peer groups, feeling different may be a disruptive and difficult experience. A disparity between parent and adolescent experiences was evident with parents describing their children as “normal.”   |
| Professional communication | The type of information and how it was communicated by health professionals was a significant part of adolescents’ experiences. More information about life post-ICD implantation would be beneficial for both adolescents and their parents.  |
| Adjusting to life          | Adolescents were able to cope well despite the significant challenges. Parents also perceived that their children had adjusted well to living with an ICD. This finding may provide reassurance for other adolescents and parents that life can continue successfully post-ICD implantation.   |
| Benefits                   | Reassurance and peace of mind were described as the main benefits of the ICD. A new finding emerged of the independence the ICD provided for two adolescents. As ICDs have previously been seen as restricting lifestyle and removing independence, this has important implications for the development of autonomy in adolescents.  |
| Ongoing challenges         | Medical appointments were a disruption to adolescents’ daily and school lives. Device replacement was also a concern described by both adolescents and parents. It is important for health professionals to be aware of these challenges, and if they are unavoidable, to take steps to minimize the impact on adolescent and family life.   |
| ICD shocks                 | Two adolescents who had experienced ICD shocks described the anticipated shock as worse than the actual experience. It is important for adolescents and parents to be informed of the variability of the shock experience to reduce anxiety surrounding the experience or expectation of the shock.  |
| Holding back               | The limitations adolescents imposed on themselves had a significant impact on peer relationships and social activities. Although this may have a protective and beneficial impact on their health and the ICD, peer experiences are important for adolescent development. Other activities in which adolescents with ICDs can fully participate should be encouraged, and parents should be made aware of the possible detrimental impact of “holding back.” |

form of device longevity has also been a significant experience of living with an ICD.<sup>19</sup>

Table II summarizes the key themes and clinical implications that emerged from the current study.

**Key Challenges for Adolescent ICD Patients and Suggestions for Managing Them**

Key challenges faced by the adolescents in this study were coping with the imposed physical restrictions, managing the anxiety surrounding the anticipation of an ICD shock, and the struggle to feel “normal” post-ICD implantation.

Finding alternatives to the restrictions associated with having an ICD was important for adolescents adjusting to life with the device, and

many spoke of finding alternatives to physical activities. Despite the challenges and restrictions these adolescents face in living with an ICD, all of the participants felt that they were able to cope successfully. This finding may be useful for other adolescents who are about to or have recently received an ICD and could also provide reassurance for parents of adolescents going through ICD implantation.

In learning to cope with the disruption their diagnosis and subsequent implantation of the ICD had on their lives, some of the adolescent participants found it helpful to frame the ICD as a potentially life-saving device. Having a positive attitude has previously emerged as an important method of coping with life for adolescents with

an ICD.<sup>7</sup> Optimism and positivity has also been described as a factor that helps adult ICD recipients to cope and adjust better to the device and reduce their anxiety.<sup>25</sup>

Several participants had been told by medical staff that the sensation of a shock was like “being kicked in the chest by a horse” (description by Jake, adolescent), which led them to believe that it would be an extremely painful experience. Of the six adolescents interviewed in the current study, only two participants had experienced an ICD shock. Both these adolescents revealed that the shock was not as painful as they had originally imagined. A variety in experiences of receiving ICD shocks has also been described by adults with ICDs, with descriptions ranging from “a tingle,” “being kicked in the chest,” to “lightning-like intensity.”<sup>22</sup> It seems for some individuals, the anticipated shock can be worse than the actual experience. This information could be particularly important for the adolescent participants who have not yet experienced the ICD shock.

Adolescence is a period where peer acceptance and conformity is sought, and so being and/or feeling different from peers can be a disruptive experience for young people. Participants spoke of their inability to do “normal teenage things,” and as a result felt different from their peers. Encouraging adolescent ICD patients to maintain physical, peer, and social activities wherever possible may help to reduce the disruption to life pre- and post-ICD implantation.

There are a number of limitations to this study. First, the sample size is small due to the limited number of adolescents who met inclusion criteria within the study site. Usually in qualitative research, recruitment continues until saturation has occurred, that is, until no new themes emerge. However, in this study, the number of available participants was the limiting factor, and therefore, it is unlikely

that saturation was reached. The six adolescent participants who chose to take part in this study may represent those adolescents who are coping best and are most resourceful. This is a common problem for research in which participants self-select.<sup>26</sup> All of the participants were patients of the Royal Children’s Hospital, Melbourne, and thus, the results of the current study are not necessarily generalizable to other populations. Lastly, the focus of this study was adolescents with cardiac genetic conditions living with ICDs as this research was conducted to fulfill the requirements of a Master of Genetic Counselling degree. However, there may also be adolescents who have ICDs for other reasons (e.g., congenital heart disease), which could have increased the sample size of the study and/or provided greater insight into the experiences of this group of young people.

### Conclusion

Despite the considerable disruptions and difficulties they face, adolescents with ICDs participating in the current study and their parents demonstrated a remarkable ability to cope successfully. Their experiences have supported previous literature in this area, and new findings related to living with an ICD have also emerged. This greater understanding of the lived experience of adolescent ICD recipients and their parents has great scope for informing future research and clinical practice.

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