

Young at Heart: Understanding the Unique Psychosocial Adjustment of Young Implantable Cardioverter Defibrillator Recipients

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SEARS, S.F. JR., ET AL.: Young at Heart: Understanding the Unique Psychosocial Adjustment of Young Implantable Cardioverter Defibrillator Recipients. *This article reviews the data related to psychosocial adjustment of young ICD recipients, postulates theories to explain potential adjustment difficulties to ICD therapy experienced by younger recipients, and suggests clinical management techniques for addressing the unique psychosocial concerns of young ICD recipients. Studies of young ICD recipients suggest that a wide range of psychosocial adjustment issues are prominent in the post-ICD implantation period and that the issues may be different from older ICD recipients. The disability-stress-coping model and the transactional-stress-coping model are postulated as explanations for the unique adjustment concerns of children and adolescents with ICDs. Social comparison theory is also applied to the concerns of young adults with ICDs such that they often lack same age peers to compare experiences with cardiac difficulties. Brief, clinic-based interventions by health care providers, like a screening and referral heuristic and an "ICD Buddy" system, are suggested to increase effective coping and decrease social isolation for young ICD recipients. (PACE 2001; 24:1113-1117)*

quality-of-life, implantable cardioverter defibrillator

Introduction

The implantable cardioverter defibrillator (ICD) has proven to be a lifesaving treatment for individuals with ventricular arrhythmias.¹⁻³ A small but significant number ($\approx 10\%$) of ICD recipients are age 50 years or younger, hereafter described as "young ICD recipients."⁴ Studies of young ICD recipients suggest that they experience significant lifestyle adjustment problems following the implantation of an ICD that are different from those experienced by older ICD recipients and may last for a greater period of time.^{5,6} These results suggest the need for a comprehensive approach to ICD patient management that spans a broad biopsychosocial model.⁷ This article provides the first review and synthesis regarding the complete care of young ICD recipients. Therefore, the aims of this article were: (1) to review the data related to psychosocial adjustment of young ICD recipients, (2) to postulate theories to explain potential adjustment difficulties to ICD therapy experienced by younger recipients, and (3) to sug-

gest clinical management techniques for addressing the unique psychosocial concerns of young ICD recipients.

Review of the Literature

A comprehensive search of the *Index Medicus* and *PsychLit* databases yielded only six studies to include in this review of psychosocial outcomes of young ICD recipients. The four studies were divided into two types: (1) descriptive studies focused solely on young recipients and (2) comparison studies with young and old ICD recipients reporting on the same issues. Given the wide age range of young ICD recipients, the group may not be homogenous, and some of the psychosocial issues faced by young recipients may be obscured. Therefore, the authors have further divided the young ICD research findings into children and adolescents and young adults populations.

Children and Adolescents

The literature on this age group is limited to only two descriptive studies. First, Hamilton et al.⁸ focused on the medical outcomes of 11 children (age range 4-16 years) immediately following ICD implantation through a 5-year follow-up. While the researchers did not focus on specific psychosocial issues, they did report that all 11 children were able to return to school shortly after

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being released from the hospital and concluded that ICDs are “safe and effective” in children who are at risk for sudden cardiac death. More recently, Wilson et al.⁹ monitored the medical and psychological outcomes of five children (age range 7–18 years) at a mean follow-up of 34 months. All five children were alive and had returned to school at the time of follow-up. Two of the ICD recipients experienced transient neurological sequelae secondary to their medical condition and the ICD; both also reportedly developed symptoms of depression and thoughts of suicide. The researchers concluded that the ICD is safe and reliable for children who have experienced syncope or have been resuscitated from sudden cardiac death and who are not responsive to antiarrhythmic drugs.

Young Adults

Dubin et al.⁶ examined quality-of-life issues for 18 young ICD recipients (age range 13–40 years; mean 28.8 years) and found that all of the ICD recipients were in “good to excellent” health and were active, productive members of society. However, a number of these young recipients experienced certain ICD related adjustment problems. The recipients reported such problems as diminished social interactions ($n = 14$), worry about and avoidance of exercise ($n = 11$ and 9 , respectively), sexual activity ($n = 9$), and body image concerns ($n = 11$) associated with clothes and appearance with the ICD.

Vitale and Funk¹⁰ evaluated the perceived quality-of-life of nine young ICD recipients (age range 13–49 years; mean 32.6 years). Six of the recipients described their life as “no better” following implantation of the ICD. Two recipients said that life was “worse” after implantation because of itching at the implantation site, perceived dependence on the device, continuous medical visits, and changes in clothing and life style. One recipient described life as “better” after receiving an ICD because they felt “protected” from sudden cardiac arrest. Sleep patterns were reportedly abnormal for the majority of the sample (8/9). Vitale and Funk¹⁰ also reported that four of the nine recipients were having problems with social isolation and that three of the nine were limiting their physical activity because of the device. Fear of shock and increased concern about dying was also reported by four of the nine recipients. The researchers concluded that patient’s quality-of-life was affected by ICD implantation and asserted that health care providers should be aware of the quality-of-life issues faced by ICD recipients.

Two larger studies provide comparisons between young and older ICD recipients.^{5,11}

Luderitz et al.⁵ assessed the quality-of-life issues of 95 ICD recipients (age range 24–76 years; mean = 56.6 years, median 57.5 years) before implantation and 12 months following implantation. Recipients who were < 50 years old had significant increases in their level of anxiety at follow-up when compared to older recipients. With the exception of younger recipients’ psychosocial concerns, recipients reported that they had adapted to the device and experienced little discomfort from the ICD.

Sears et al.¹¹ conducted a national survey of ICD recipients who had been implanted with an ICD for < 1 year. Results from the study of 450 recipients indicate that ICD recipients report significant quality-of-life benefits from their ICD. However, approximately 10%–20% of those surveyed reported difficulty with emotional adjustment. Recipients ≤ 50 years of age reported better general health, but worse quality-of-life and emotional functioning than older ICD recipients. Those recipients who received more shocks from their ICD, women and younger recipients, reported significantly more adjustment concerns such as generalized fear, worry, fear of physical exertion, depression, and difficulties managing stress.

Taken together, the studies of young ICD recipients suggest that a wide range of psychosocial adjustment issues are prominent in the post-ICD implantation period and that these issues may be different compared to older ICD recipients. The small sample sizes and/or descriptive nature of some of these studies warrants caution when interpreting their results.

Theoretical Approaches to the Psychosocial Adjustment of ICD Recipients

General Theories of Psychological Adjustment to the ICD

A recent literature review summarized three relevant theories that hold heuristic value in explaining the adjustment of ICD recipients across age groups.¹² First, *Classical Conditioning* can be used to explain how repeated shocks given by the ICD may be paired with previously neutral environmental or behavioral stimuli, resulting in conditioned responses including anxiety or fear.¹³ Second, *Learned Helplessness* theory can be used to explain how ICD recipients who feel as if they have no control over the necessary defibrillation discharges may develop feelings of hopelessness and depression about their current and future health status.¹⁴ Sears et al.¹² proposed a third theory, *Cognitive Appraisal Theory of ICD Activity*, as a model for how some ICD recipients seek greater perceived cognitive control by interpreting the activity or inactivity of the device as an indicator of

their level of current cardiac functioning. Recipients use the firings of the device as a "sickness scoreboard," believing that when the device fires they are becoming sicker and when it does not fire that their health is improving.

Age-Specific Theories of Adjustment

To address familial role issues and other stressors that would be obscured if young ICD recipients were considered as one group, the authors again divided the group into those 18 and younger (children/adolescents) and those 19–50 years of age (adults).

Children and Adolescents

No comprehensive theory of adjustment specific to children who have received an ICD has been published. To fill this void, we have found it useful to draw material from the literature on children with chronic illnesses. While a ventricular arrhythmia is an event rather than a chronic illness, it is a life-threatening condition that must be monitored and treated for the life of the patient. Therefore, analogies to children with chronic illness can be made.

Wallander and Thompson¹⁵ asserted that the wide range of special psychosocial adjustment challenges faced by children with a chronic illness put them at "increased risk for mental health and adjustment problems." In their disability-stress-coping model, Wallander and Varni¹⁶ propose three categories of risk factors that may contribute to the maladjustment of children with a chronic illness:

1. Disease and disability parameters include factors like type of diagnosis the child has received, the level of physical and behavioral impairment caused by the condition, the visibility of the condition, and if cognitive functioning is impaired by the condition.

2. Functional dependence in activities of daily living. In other words, can the child walk, talk, eat, dress, etc., without assistance?

3. Psychosocial stressors include disability problems, major life-events, and daily hassles.

According to the disability-stress-coping model, when children experience increased stress associated with their condition that may be related to disability parameters or functional dependence, these condition related stressors increase the effects of daily life stressors already experienced by children and psychosocial adjustment problems develop. Furthermore, the disability-stress-coping model postulates that adjustment is influenced by resistance factors. These factors fall under three categories: 1. personal factors such as problem-solving abilities, temperament, and moti-

vation, 2. social-ecological factors including familial resources and social support, and 3. stress-processing abilities such as coping strategies and cognitive appraisals. The researchers postulate that if the child has an adequate number of resistance factors he or she may be less vulnerable to psychosocial adjustment disorders.¹⁶

Clinical experience with children who have ICDs suggests many applications for the theory of Wallander and Varni. For example, perceived physical limitations may make going to school especially stressful for young ICD recipients. Also, the inability to predict when the device might discharge and the fear of the discharges may compound the stress of interacting with peers and lead to increased social anxiety. Finally, resistance factors, like a strong family support system, may facilitate adjustment to the real and perceived limitations of young ICD recipients.

A second model of adjustment was extended by Thompson et al.¹⁷ who proposed a transactional-stress-coping model based on an ecological-systems approach to understanding stress and coping in children with chronic illnesses. The model focuses on the transactions between biomedical, developmental, and psychosocial systems and how familial and extrafamilial systems affect illness outcomes. Furthermore, Thompson hypothesized that the adaptational processes of the child and other family members, specifically the mother, are the key factors that affect the child's psychosocial adjustment.¹⁷

Adaptational processes are described as expectations about self-esteem, the child's health locus of control, how caregivers appraise stress, familial functioning, and methods of coping for the child and the caregivers. Adaptational processes are thought to affect the adjustment of the chronically ill child above and beyond medical and demographic variables.¹⁵ Appropriate adaptational processes may be seen as similar to the resistance factors described by Wallander and Varni,¹⁶ the disability-stress-coping model; the more appropriate the processes, the less vulnerable a child is to maladjustment.

Young Adults

The adjustment of young adult ICD recipients may be explained by the social comparison theory, which hypothesizes that when no objective standard is available for a person to test their abilities directly, they compare themselves to others.¹⁸ Early research on the social comparison theory and coping with major medical problems indicated that individuals suffering from major illnesses may not seek or be given information they can use to understand their illness or modify its outcome; this makes an objective self-evaluation

improbable. They may suffer from lowered self-esteem if they see themselves as victims or they are perceived by others to be victims. Finally, they may experience distress that cannot be controlled or mediated by problem-focused coping, thereby increasing their feelings of helplessness.¹⁹

The social comparison theory also asserts that individuals compare themselves to groups of people or other individuals to whom they feel similar. The small number of adults aged 19–50 years with ICDs may result in a lack of communication between individuals in this age group. This lack of communication with other young ICD recipients may lead to comparisons with other people in their age group who do not have ICDs or related heart arrhythmia concerns (i.e., individuals who are working, active, and physically fit). These comparisons may result in lowered self-esteem and unrealistic self-evaluations and consequent adjustment difficulties.

Clinical Management Strategies

The successful management of psychosocial issues requires continuous monitoring and follow-up by the full range of health providers. Sotile and Sears²⁰ provide a clinic-based strategy to help physicians and allied professionals to address the adjustment difficulties of their ICD recipients. The strategy was adapted from a behavioral modification program for clinic-based smoking cessation program.²¹ Sotile and Sears²⁰ suggest *The Four A's Checklist* to detect and manage psychosocial issues in ICD clinics with the four A's: ask, advise, assist, and arrange (Table I).

The first item on the checklist is to *ask* the patient about their ICD related concerns in an effort to accurately define their perceived problem. Health care needs are important for all ICD recipients and should be the focus of their physician's assessment. However, the unique concerns of young ICD recipients must also be carefully considered. For children with ICDs, the family's adaptational processes should be evaluated alongside the child's adjustment. Issues such as caregivers' stress, emotional health, and economic position should be taken into account. For young adults with ICDs, discussion of peer relationships and self-comparisons to their abilities and limitations relative to physical activities, emotional stability, and cognitive functioning can provide some clues about overall adjustment. Understanding these issues will allow clinicians to effectively use the remaining A's when designing individualized treatment plans.

Second, the healthcare provider can *advise* the ICD patient on the common challenges that lie ahead and how to manage these concerns via supportive communication.²² The healthcare provider

Table I.

The Four A's Checklist for Helping Patients Cope with Implantable Cardioverter Defibrillators (ICDs) From Sotile & Sears, 1999.

ICD Provider Checklist for Helping Patients Cope

The Four A's:

ASK
ADVISE
ASSIST
ARRANGE

ASK	<i>Assess concerns</i> Clarify patient concerns to identify exact problem.
ADVISE	<i>Anticipate psychosocial impact</i> Provide psychosocial intervention from the outset of care.
ASSIST	<i>Be practical</i> Address specific issues that matter to the patient now. <i>Educate</i> Teach patients about their condition and their device. <i>Support</i> Allow patients to describe feelings and personal challenges. <i>Use your experience</i> Forecast and communicate what will happen next for the patient and family.
ARRANGE	<i>Refer PRN</i> Refer patients who would benefit from consultation with a mental health specialist. Set up support group participation, stress management classes, and other locally available programs.

vider should take care to respect the coping style and adjustment difficulties of each patient. Third, the provider can *assist* the patient by addressing the immediate concerns of the patient, educating the patient about their device, and providing some problem-solving assistance for the specific concerns reported.

Fourth, the health care provider should *arrange* a consultation for those recipients who would benefit from speaking with a mental health specialist. The referral may be best framed as a referral for "stress management" related to their medical condition and current adjustment. For children with ICDs, it is important that the referral be made for the entire family to ensure that the primary caregivers of the child are part of the

mental health treatment plan. Young ICD recipients may also benefit from being given the option of serving as or being given an "ICD Buddy" to another young ICD recipient. This would provide them with appropriate social comparisons and allow them to expand their social support network.

Additional strategies for the management of young ICD patient adjustment include discussion about the relative perspective of being a "victim" of cardiac arrhythmias versus a "survivor with a lifeguard." This orientation to their health condition and their ICD represents an important distinction in the adjustment process.

Acknowledgement of the significant changes that their condition and device have brought can often help begin the shift from victim to survivor. These discussions are often well-rounded by a dialogue about a young patient's hopes and plans for the future. Young recipients, more than any other age group, need to have specific events and accomplishments that they are striving toward to maintain positive adjustment over the course of care.

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Conclusions

Young ICD recipients represent a unique subset of cardiac patients with different expectations and psychosocial adjustment challenges. Empirical research suggests that children and adolescents who receive ICDs are able to return to school with few limitations. Psychological theory and research have suggested that young ICD recipients may experience increased stress associated with their medical condition and minor activity limitations relative to their peers. Young ICD recipients may also experience stress from engaging in social comparisons with their peers, such that young ICD recipients conclude they are very "different" from all other peers who do not have health conditions or limitations whatsoever. Routine clinical assessment using the four A's of ask, advise, assist, and arrange provided in Table I may serve as a useful clinical heuristic to guide health care providers to reduce distress. Young ICD recipients are committed to a lifetime of utilization of ICD technology and addressing their adjustment challenges to the device may be the key for recipients deriving optimal quality of life.