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Psychosocial Factors Related to Living with an Implantable Cardioverter Defibrillator and Proposed Strategies for Success

Lauren D. Vazquez, PhD

Coping with treatment with an implantable cardioverter defibrillator (ICD) can certainly be considered a life-changing experience. As with any significant life event, the process of adjustment can be challenging. Research has shown that ICD patients face common difficulties after implantation of their device. My work as a clinical health psychologist has been focused on identifying those difficulties and helping patients develop strategies to adjust to treatment adaptively and embrace the best quality of life possible. The purpose of this chapter is to describe the psychosocial concerns that are common in ICD patients and to propose a set of coping skills that can help you be more successful in living life to the best of your ability.

Psychosocial Concerns

Life may bring many stresses over time as we experience change, loss, or hardship. Coping with treatment with an ICD may represent one of those changes that you find stressful. Stress is a term to describe the entire set of challenges, frustrations, and changes that we all deal with on a daily basis. We know that ICD patients cope with a unique set of stressors that may create an equally unique set of concerns. Approximately 15% of patients will experience what is considered significant emotional distress (Sears et al., 1999). Distress may include anxiety (often centered on the potential for ICD shock), depression, family concerns, or other device-specific adjustment difficulties. Risk factors for distress include being female, being young (under the age of 50), patients with limited social support, those with a limited understanding of their heart condition or how their ICD functions and those patients who have a previous history of ICD shock (Sears & Conti, 2002). However, while psychological distress may not be uncommon, research suggests that overall ICD patients generally report good quality of life (Schron et al., 2002; Irvine et al., 2002). Quality of life refers to one's personal satisfaction with the life they are living. Being prepared with adaptive coping skills can also help ICD patients minimize the impact of device-specific concerns and enhance their quality of life.

Our minds and our bodies are programmed to respond to a variety of physical, mental, and social stressors. Because stress can manifest in these different ways, it is vital to be prepared with adaptive strategies to respond to those stressors. If we are not armed with effective coping strategies, it is easy to see oneself as a victim of our experiences. It is not uncommon for ICD patients to feel victimized by their heart problems and treatment experiences. Some may even view their device as an unwelcome reminder of their condition. This pattern of thinking can lead to the development of anxiety. Anxiety is a basic emotion that we all experience from time to time. While anxiety is an emotion that is both natural and necessary for healthy functioning, it is important to recognize when anxiety becomes maladaptive, or in other words, when it begins to have a negative impact on your daily lives. Anxiety can be experienced in three different types of symptoms; cognitive symptoms like your thoughts or fears, behavioral symptoms such as your actions or responses, or physical symptoms such as bodily sensations.

Patients living with an ICD often experience a variety of anxiety symptoms. About 13 to 38% of patients experience significant symptoms of anxiety (Sears et al., 1999). The most common anxiety symptoms for ICD patients include thinking negatively or fearfully about the device, avoidance behaviors, and bodily hypervigilance. Fear is certainly an understandable experience for the ICD patient, given the potential for something as unique as ICD shock. As humans we tend to fear the unknown; the unpredictability of the shock experience and the aversive nature of pain can certainly lead someone to fear the potential for shock. However, most patients report that shock is not significantly or lastingly painful. So while a patient might have a natural tendency to think the experience of shock might be very negative, the reality is that it is typically described as just being startling or surprising.

Many patients attempt to act in certain ways that they think will reduce their chances of receiving a shock. This often includes avoidance of particular situations, objects, or activities. While these avoidance behaviors reflect an attempt for control of a seemingly uncontrollable situation, this often leads to deficits in quality of life and even more distress and fear. This is particularly true for patients who avoid perceived triggers that were previously very positive experiences – such as the child who avoids sleepovers for fear of having a shock at someone else's home, or the young adult who chooses to leave college after having been shocked on campus, or the husband who avoids hugging his wife or children for fear of hurting them in the event of a shock. It is important to realize that avoidance is an entirely ineffective strategy! An ICD can fire at any time, in any place, in any situation, making the avoidance of perceived triggers a hopeless effort.

Bodily hypervigilance simply refers to paying excessive attention to one's bodily symptoms. Patients with ICDs who exhibit hypervigilance may constantly scan their bodies for any changes in physical sensations that they believe may signal an impending shock. However, much like avoidance, while hypervigilance may help patients feel like they have more control over their device functioning, it is actually a useless strategy for preventing shock.

Depression may be present in about 24 to 33% of ICD patients (Sears et al., 1999). Symptoms of depression can be related to feeling like the device is limiting your ability to function or live life the way you want to. Feelings of sadness, hopelessness, or not enjoying things you once did are also common symptoms of depression. Patients most at risk for developing depression may include those with a history of ICD shock, as they struggle with interpreting their device and treatment experience as something positive.

Proposed Strategies for Success

When you are faced with unique challenges it may be easy to find yourself feeling isolated as you struggle to make sense of your situation. But it is essential to realize that YOU ARE NOT ALONE! Many people coping with ICD treatment experience frustration that they are just not living life the way they want to. Being prepared with effective ways to deal with the stress of ICD treatment is essential in taking control of living life the way you want to. The following strategies emphasize promoting better quality of life while coping with the stress of treatment with an ICD.

1. Develop a shock plan

Because you have an ICD, you are automatically protected from dangerous heart rhythms. Your ICD protects you by constantly monitoring your heart; when the device detects an abnormal rhythm, it delivers a shock that restores normal heart rhythm. Although shock may be something a patient wishes to avoid, shock is an indication that the ICD is doing its job, keeping you protected. It can be helpful to plan ahead for shock, so that you and your loved ones have a clear understanding of how to handle the situation. Having a plan in place ahead of time can reduce some of the stress that may occur after receiving a shock. Discuss developing a shock plan with your healthcare team so that you can feel prepared should you ever experience a shock in the future.

2. Promote family adjustment

Adjustment to life with an ICD takes time. Living with a device may create changes for you or for members of your family. It is normal to feel stress or guilt because of these changes. But it is essential to remember that all families are faced with events that initiate change. Whatever the initiating factor may be, it is important to remember that families are connected as a team. Changes within the family need not be negative. In fact, many patients describe their family as being stronger after dealing with the challenges of treatment with an ICD. Family adjustment is certainly an ongoing process that requires time and energy by all members. It is normal to experience changes in the family, both positively and negatively. Any problems you had before your device implantation are unlikely to have gone away. Being able to talk openly about your feelings can help you to work out solutions together. It is important for all members of the family to identify their needs and acknowledge them by maintaining healthy interests and activities.

3. Take time to relax

Relaxation is the act of letting go of the stress and worry you may be experiencing. Learning effective ways to relax and let go of tension can lead to a sense of calm and serenity. Learning to control your breathing is a powerful tool for relaxation. By focusing your attention on taking slow, deep breaths you can take control of allowing your mind and body to relax. Deep breathing is a tool you can utilize in a variety of settings - during doctor's appointments, lying in bed at night, or in any of the daily situations you find stressful. Identify how you feel after breathing deeply. Make a list of situations in your daily life where breathing deeply may be helpful.

4. Communicate with your healthcare team

Developing effective communication with your healthcare team is a vital component of taking control of your health and well-being. Misunderstandings about the purpose and function of the device are not uncommon. Do not hesitate to ask questions about your ICD, heart condition, or medications. Write questions down ahead of time and bring to your appointments to facilitate communication. Request educational materials from your providers. Being an informed patient will reduce misconceptions about the ICD and may decrease your risk of developing emotional distress. Being proactive about gaining knowledge about your health will help you feel more confident and in greater control of your treatment experiences.

5. Schedule pleasurable events

Part of taking control of your emotional well-being involves intentionally scheduling rewarding activities that you commit to follow through with. It makes sense that when you start doing fun or pleasurable activities you may begin noticing that life feels a little more rewarding again. Identify some activities that you can schedule for yourself to help the good things in your life feel enjoyable again. Make sure you follow through with participating in these activities despite any fear or discomfort.

6. Maintain physical activity

Regular physical activity can improve your health and quality of life in a number of ways. Exercise helps maintain a better mood, assists in regulating biological rhythms, and is a vital component of controlling weight. Routine exercise is also a healthy way to keep stress at a minimum and increase energy. Discuss some physical activities that are safe and enjoyable with your healthcare team. Identify some of the personal benefits you might gain in participating in physical activities.

7. Decide what is really important to you

People who are faced with implantation of an ICD may be forced to look at life a little differently. Studies suggest that individuals with health issues who are able to adjust appropriately actually report feeling more resilient than before their illness. This is the idea of gaining strength through hardship. If a person can navigate the stress of coping with treatment with an ICD successfully by continuing to embrace what is really important to them, the quality of their life can be better than ever. Deciding what is truly important to you – family, spirituality, or anything you find intrinsically rewarding – is a vital step in improving your quality of life.

8. Consult a professional

Even if you know strategies to deal with your difficulties, at times stress can still become too overwhelming to handle on your own. Despite all of your efforts, there are times when stress cannot be handled by one person any longer. When that occurs, seeking the help of a professional is the best way to gain support in dealing with what you are experiencing. It is not uncommon for people dealing with health issues to develop psychological symptoms. Many seek help from a mental health professional in order to better manage or cope with their feelings. It is important to be able to recognize when it may be beneficial to enlist the help of a professional.

Keep in mind that implementing change in your life is a process – it is something that takes time and commitment. Using the skills and strategies outlined in this chapter should provide you with the building blocks to facilitate the process of enhancing adjustment to treatment with an ICD and making changes in your life that you desire. I encourage you to go back and read the material frequently and share what you have learned with your family and friends. I hope that this knowledge, in combination with regular follow-up care by your healthcare team, will help you take control of creating the life that you want to live. Remember that challenges are expected. Coping effectively with treatment with an ICD helps you to change your mindset from being a victim of heart disease to celebrating life as an ICD survivor. I commend you in your ongoing journey and hope that this information helps you take a step forward in facilitating the process of adjustment and creating the quality of life that you desire.

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Additional Resources:

How to Respond to an Implantable Cardioverter Defibrillator Shock; Samuel F. Sears Jr, PhD, Julie B. Shea, MS, RNCS, and Jamie B. Conti, MD
Available at: http://circ.ahajournals.org/content/111/23/e380

How to Respond to an Implantable Cardioverter Defibrillator Recall; Kari B. Kirian, MA, Samuel F. Sears, PhD, and Julie B. Shea, MS, RNCS, FHRS
Available at: http://circ.ahajournals.org/content/119/5/e189

Coping with my Partner's ICD and Cardiac Disease; A. Garrett Hazelton, MA, Samuel F. Sears, PhD, Kari Kirian, MA, Melissa Matchett, PsyD, and Julie Shea, MS, RNCS, FHRS
Available at: http://circ.ahajournals.org/content/120/10/e73

Sexual Health for Patients with an Implantable Cardioverter Defibrillator; Lauren D. Vazquez, PhD, Samuel F. Sears, PhD, Julie B. Shea, MS, RNCS, FHRS, and Paul M. Vazquez, DO
Available at: http://circ.ahajournals.org/content/122/13/e465