

Life with an Implanted Cardioverter Defibrillator (ICD)

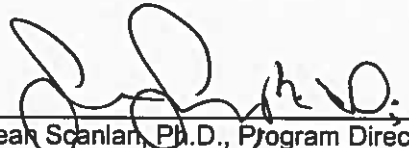
Shantha McKinlay

A clinical research project submitted to the faculty of Hawai'i School of Professional Psychology at Chaminade University of Honolulu in partial fulfillment of the requirements for the degree of Doctor of Psychology in Clinical Psychology.

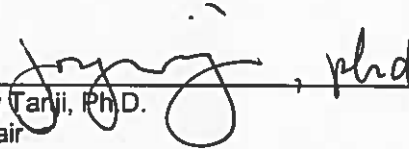
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This Clinical Research Project by Shantha McKinlay, directed and approved by the candidate's Clinical Research Project Committee, was approved by the faculty of the Hawai'i School of Professional Psychology at Chaminade University of Honolulu in partial fulfillment of the requirements of the degree of Doctor of Psychology in Clinical Psychology.


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Shantha McKinlay

Hawai'i School of Professional Psychology at Chaminade University of Honolulu – 2019

The current literature indicates increased depression and anxiety among individuals with an implantable cardioverter defibrillator (ICD). The anxiety and depressive symptoms associated with an ICD can lead individuals to develop serious mental health concerns. Despite these emergent findings, there is limited research on the mental health concerns of individuals with ICDs and their experiences, particularly among young adults (Sears, Kovacs, Azzarello, Larsen, Conti, & Kenkel, 2004; Van Lommel, Van Wees, Meyers, & Elfferich, 2001). The purpose of this study was to examine the experiences of a young individual living with an ICD in order to enhance awareness to these experiences and to be used to inform future studies of health care practices that explore ways to address the mental health of these patients more meaningfully. This study explored the narrative of a young adult male who experienced an out-of-hospital sudden cardiac arrest and has been living with an ICD for about seven years. He had the device implanted when he was 22 years old and a senior in college. The findings of this study revealed a recurring theme of *trying to find normalcy*.

Dedication

I would like to dedicate this project to all of the skilled professionals and individuals in 2011 who made sure that I stayed alive. I literally would not be here today without you.

I would also like to dedicate this academic work to my parents, Shantha and Joseph, and my brother and sister, Kenneth and Alexandra. Thank you for putting your life on hold to make sure I could continue mine. I would not be who I am without you.

Finally, I would like to dedicate this project to my participant, JR. I am glad you are still here. You truly are a superhero with great strength and positivity.

Acknowledgements

JR, I cannot express how grateful I am to have shared this experience with you. It has changed my life for the better. Thank you for your openness and for trusting me with your story. I could not have done this study without you.

I would like to thank Dr. Joy Tanji, my committee chair, for her unlimited guidance and patience during this research project. I would also like to thank my committee member, Dr. Michael Omizo, for dedicating his time and energy to this project. You both have been a constant source of support and positivity throughout the course of this research project and throughout the doctoral program.

I would also like to thank my parents for all the opportunities you have given me. You have provided unwavering encouragement in all of my academic endeavors. Ken and Alexandra, thank you both for proofreading all of this and making sure I finish my slides. Finally, Chris, thank you for taking such good care of my heart.

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CHAPTER I. INTRODUCTION

An Implantable Cardioverter Defibrillator (ICD) is a life-saving device for individuals with ventricular arrhythmias and those at risk for sudden cardiac arrest. Newer ICDs include a pacemaker component (American Heart Association, 2016). Survivors and family members of survivors of cardiac arrest experience symptoms of anxiety, depression, and other psychosocial impairment (Dunbar, 2005). There is limited research on the experiences of young individuals with ICDs. This omission, as will be elaborated later, has major implications for the optimal care of cardiac arrest survivors and their families.

Situating the Study

I began this journey by situating the study that follows. Situating a study provides the reader with a better understanding of the motivating factors behind the study. A researcher might have both personal and practical goals that motivate her to conduct a study (Glesne, 2016). By situating the study, the researcher provides readers with an important context for understanding some of the limitations of the study as well as the approach to the study (Glesne, 2016).

When I was 19 years old, a sophomore attending college on the East Coast, I experienced a sudden cardiac arrest. I was found face down in the snow and was rushed to the hospital nearby. My family was at home in Hawai'i. They were called early in the morning, the morning of my sister's fourth birthday. My mom answered the call and was told by my aunt that I was in the hospital and that she needed to call the doctors. My mom woke my dad and relayed the shocking news. My parents, 11-year-old brother, and four-year-old sister were on the next flight they could catch to Philadelphia.

I stayed in the Intensive Care Unit (ICU) for three out of the four weeks of my hospital stay. I endured months of physical, occupational, and cognitive therapy. After begrudgingly wearing an external defibrillator, not the most flattering accessory, I was scheduled to have an ICD implanted, approximately five months after my cardiac arrest. I have had my ICD for eight years and the battery of the device will need to be changed in the near future.

Five years prior to my cardiac arrest, during my freshman year of high school, I passed out on the baseball field during the first day of softball tryouts. I woke up confused and on the ground, heads hovered over me. I spent that Halloween in the emergency room. I followed up with a cardiologist and

even sought a specialist in the very same hospital where I received my ICD. This incident was the first and only indication of my risk for cardiac arrest.

I am privileged to have parents who are both physicians. Their medical knowledge ensured that I would have the best care and the best outcome. I have relied heavily on their expertise and support to navigate through recovery and my follow-up visits with doctors. This experience has impacted my life and my family members in a multitude of ways. It has shaped how I view myself, others, and the world around me. Upon reflection, I find myself having more strength and determination than I could imagine. It has given me a greater appreciation for and understanding of other's traumatic experiences. At the same time, my experience and medical condition leave me facing situations and decisions that most people my age do not have to consider. Most things I do come at a higher risk.

I have often wondered how other young adults deal and cope with having an ICD and their underlying cardiac challenges. I have not had the opportunity to encounter and speak with people that have an ICD. The patient's experience of living with an ICD is an important area of study that may help improve practice and give health care providers a better understanding of the individuals they treat. This will also help normalize the common experiences of individuals living with an ICD or those who have experienced similar medical complications.

Review of Literature

In beginning this process, I went to the current literature. A review of literature explores the potential focus of the study in relation to the relevant extant theory and research on a phenomenon. It offers the reader an integrated look at the current knowledge base relevant to the phenomenon being studied. A literature review provides the qualitative researcher with an overview of what is known and unknown or poorly understood about the phenomenon under study. This provides an important context for the study (Rossman & Rallis, 2012). It also supports the researcher in examining the moral praxis or ethical value of the study. The researcher uses the review of literature to consider whose experiences are underrepresented or omitted from the current literature, and the social cost of this omission (Glesne, 2016). The review of literature also enhances the researcher's theoretical sensitivity. It is important for the

researcher to know what is meaningful to ask in order to avoid a Type III error or asking meaningless questions (Kirk & Miller, 1986).

Sudden Cardiac Arrest and Implantable Cardioverter Defibrillators: The Basics

The heart plays a vital role in the body. The heart pumps blood to other areas of the body. Electrical impulses in the heart travel from the upper chambers of the heart, or atria, to the lower chambers of the heart, the ventricles, via the atrioventricular node. The electrical impulses sustain normal blood flow to and from the heart. The electrical impulses cause the heart to contract and beat (Sears, Kovacs, Azzarello, Larsen, Conti, & Kenkel, 2004).

Etiology

Sudden cardiac arrest (SCA) and *sudden cardiac death (SCD)* refer to the abrupt stop of cardiac mechanical activity often due to ventricular tachycardia or ventricular fibrillation (Podrid, 2019). If the heart restores circulation, either spontaneously or by defibrillation, the event is referred to as an SCA. However, if the individual dies, the event is referred to as an SCD. Globally, *out-of-hospital cardiac arrests (OHCA)*, arrests that take place outside of a hospital, are one of the leading causes of death (Kyoung-Jun & Rea, 2018).

The causes of OHCA can be placed into two broad categories, cardiac and non-cardiac issues. Most individuals who experience an OHCA have a cardiac cause. The most common result of cardiac arrest is cardiac death. Sudden cardiac arrest typically occurs in individuals with some type of structural heart disease, most commonly coronary heart disease (CHD). Approximately 70% of sudden cardiac arrests have been attributed to CHD. Other structural heart diseases that lead to out-of-hospital sudden cardiac arrests include heart failure and cardiomyopathy, myocarditis, congenital coronary artery anomalies, mitral valve prolapse, valvular abnormalities, and congenital channelopathies (Podrid, 2019).

Arrhythmias in the heart are changes in the heartbeat's speed or rhythm. These are typically attributed to abnormalities in the electrical circuit of the heart. *Bradycardias* are slow heartbeats and are typically treated with a pacemaker. *Tachycardias* are fast heartbeats and can be treated with medications, an ICD, or both. Ventricular tachycardias can inhibit the heart's ability to pump blood and maintain normal

blood pressure. This can cause an individual to experience dizziness and, in some cases, faint (Sears et al., 2004).

Sudden cardiac arrest, although rare, is also associated with athletic activity. It is the leading cause of death in athletes. Most sudden cardiac death instances in athletes are caused by malignant arrhythmias. In some cases, there can be changes in the cardiac structure due to prolonged physical training. The demands of rigorous athletics may also trigger malignant arrhythmias (Pelliccia & Link, 2019).

Cardiac Arrest, Not Heart Attack

Heart attacks are often confused with cardiac arrests. *Heart attacks* are a result of complications with circulation due to a block in blood flow to the heart. Heart attacks are also referred to as a myocardial infarctions. *Myocardium* refers to the heart's muscles and *infarction* refers to any interruption of blood flow that damages tissue permanently. Symptoms of a heart attack include pain or heaviness in the chest, shortness of breath, and sweating (Heart attack vs. sudden cardiac arrest, 2004). Risk factors for heart attacks include smoking, family history of heart attacks, hypertension, high cholesterol, and obesity. Heart attacks also increase the risk of cardiac arrest (Medtronic, 2015).

Cardiac arrests are the results of electrical malfunctions in the heart that prevent blood flow and oxygen to the brain. They cause the heart to suddenly stop beating. If the heartbeat is not restored, it results in death (Heart attack vs. sudden cardiac arrest, 2004). Risk factors for sudden cardiac arrest include family history of sudden cardiac arrest, heart failure, abnormal heart rhythm, and a history of heart attacks. Typically, individuals who have a sudden cardiac arrest do not have any symptoms, but they might experience dizziness, fainting, lightheadedness, or a racing heartbeat (Medtronic, 2015).

Prognosis

A person's prognosis following a sudden cardiac arrest, or the sudden loss of heart function, improves with immediate chest compressions and defibrillation. Ventilation provided in cardiopulmonary resuscitation (CPR) plays a less imperative role. Defibrillation devices might not be readily available (Sovari, 2017). Longer periods of CPR often indicate a poor outcome. Individuals who experience a cardiac arrest outside a hospital environment have a poorer prognosis. The rate of survival for an out-of-

hospital cardiac arrest is less than 6%, according to the Institute of Medicine (as cited in Berger, 2017). The hospital that admits the patient immediately following the cardiac arrest also impacts survival outcomes based on their treatment capacity. Factors that influence a higher probability of survival to hospital discharge include witnessed arrest, pulse regained within the first 10 minutes of CPR, identification of early warning signs, ventricular tachycardia (VT) or ventricular fibrillation (VF) as the initial rhythm, and a dedicated resuscitation team (Podrid, 2019).

The brain plays a major factor in the outcome following the survival of a cardiac arrest and reviving the heart. The brain is the most vulnerable organ during a cardiac arrest. When heart function stops, the body experiences a lack of oxygen and blood flow. Damage to the brain and other organs is determined by the amount of time before the heart and blood flow are restored. Hypothermia therapy is a treatment that has been used in these patients in order to improve brain health and reduce anoxic brain injury (Anderson & Vega, 2017). A higher body temperature is associated with poorer neurological outcomes. It is also important that individuals who experience SCA are given a neurological evaluation to assess for any impairment due to the cardiac episode (Podrid, 2019).

Implantable Cardioverter Defibrillator

An Implantable Cardioverter Defibrillator (ICD) is a life-saving device for individuals with ventricular arrhythmias and those at risk for sudden cardiac arrest. Individuals might have a history of heart attacks or heart failure. ICDs are the initial therapy recommended for survivors of cardiac arrest. Ventricular tachycardia (VT) is the underlying cause for a majority of sudden cardiac arrests in America. VT is defined as having a heart rhythm that is faster than 100-120 beats per minute and having three or more irregular heartbeats in a row (Compton, 2017). About 800,000 people have ICDs in the United States and approximately 100,000 ICDs are placed per year (Medtronic, n.d.).

An ICD is an electronic device that is placed under the skin that monitors the heart. Wires, or leads, connect the ICD and the heart. If the ICD detects an abnormal rhythm, a fast heartbeat, the device will deliver an electrical shock to restore the normal heartbeat. The shock intensity varies. Shocks have been described as getting kicked or punched in the chest or being struck by thunder or lightning. Some individuals also report phantom shocks (Ahmad, Bloomstein, Roelke, Bernstein, & Parsonnet, 2000). All

modern ICD devices function as both a defibrillator and a pacing machine (Beyerbach, 2017).

Pacemakers stimulate the heart if the heartbeat is detected as being too slow (American Heart Association, 2016).

The procedure to place the ICD usually takes a few hours. During the procedure, one or more leads or insulated wires are inserted into the veins near the collarbone and guided toward the heart. The leads are then connected to the heart on one end and the generator on the other end. Up to three leads can be placed in the heart (Knight, 2019). The generator is implanted under the skin close to the collarbone. During the procedure, the physician also tests the ICD. This might require increasing the individual's heart rate and using the ICD to shock the heart into normal rhythm (Implantable Cardioverter Defibrillator, 2017). Surgical risks include collapse of the lung, perforation of the heart, bleeding, infection, dislodgement of the defibrillator, and death. Long-term risks include infection or erosion of the device, lead failure, inappropriate detection, and premature battery depletion or device failure (Knight, 2019). Following the procedure, the patient is left with a visible scar. The edges of the device can also be felt. Newer devices are significantly smaller in size, about the size of a pager (Webster et al., 2014).

For the month following the procedure, patients are advised to refrain from lifting objects that weigh more than five pounds, intense above the shoulder exercises, and contact sports. There are also long-term precautions for individuals with an ICD. This includes keeping cell phones and music devices away from the ICD implantation site. Metal detectors, like at an airport, might interfere with or set off the ICD. Magnets and power generators can also interfere with an ICD. Magnetic resonance imaging (MRI) and magnetic resonance angiography (MRA) are not recommended for those with an ICD; however, newer devices might enable this (Implantable Cardioverter Defibrillator, 2017). Unfortunately, individuals with an ICD are also unable to visit the Hoover Dam due to its high magnetic field.

Individuals with ICDs require regular outpatient visits in order to monitor the device, including battery and lead status. Individuals usually follow up with their physician, typically an electrophysiologist, every three to six months. The device can be examined using a programmer that is placed on the area on the chest where the ICD is placed (Knight, 2019). Battery life is predictable and typical devices last for about 5-10 years. The battery life decreases with increased number of shocks. Lead problems are less

predictable. Many patients also remain on medications, such as beta-blockers, to help treat their condition in conjunction with the ICD (Compton, 2017).

The ICD also records the heart's activity. The information can be obtained during an office visit or through in-home, remote monitoring (Knight, 2019). The patient has a small in-home patient monitor that uses cellular technology. It can be used to send information from the ICD to the patient's cardiologist. The physician and patient can schedule information to be automatically sent. Typically, the information is sent while the patient is sleeping. The physician can remotely read and review the information over a secure network. It allows the physician to easily manage and monitor the patient's condition and obtain information as needed (Medtronic, 2015).

Individuals with an ICD are also advised to inform their other treating physicians, dentists and other healthcare providers to discuss the risks or benefits of any necessary procedures or treatments. Some treatments for other health issues can interfere with the ICD. It is encouraged that individuals wear a medical identification bracelet in the case there is an emergency in which the patient cannot communicate (Knight, 2019). The bracelet can include information such as the patient's health condition, drug allergies, emergency contact or physician.

A review on the data regarding the risks of ICDs in young adults, individuals between 16 and 45 years old, established six primary risks of having an ICD: (1) implantation risk, (2) infection, (3) inappropriate shock, (4) imperfection, (5) insufficiency, and (6) insurance risk. Although younger individuals are not at greater risk for their initial implantation, many of them have a potential need for re-implantation due to the limited battery life. Risks of implantation alone might include unexplained pain, pocket infection or erosion, lead dislodgement, coronary embolism, stroke, or even death. Fortunately, the risk for stroke and death is relatively low (Sherrid & Daubert, 2008). Young women with ICD devices also have an added risk during pregnancy and delivery. An ICD might have to be reprogrammed in order to avoid unnecessary shocks during this period (Howell & Schwartz, 2015). However, women who get pregnant with an ICD can do so without any increased risk to her or the fetus (Knight, 2019).

Infections of cardiac devices are not uncommon. These infections typically require hospitalization. Replacement of the device might be required. Device replacement is a costly treatment, though.

Repeated device replacement further increases the risk of infection. Infection of the device is typically remedied by removing both the lead and device. Aggressive early intervention, antibiotics, and removal of the device has shown positive outcomes with over a 90% cure of infection (Sherrid & Daubert, 2008).

Diastolic hypertension and smoking have both been indicated as factors that might contribute to inappropriate shocks. Lead failure and over-sensing can cause the ICD to go off unnecessarily and administer shocks, too. Lead failures cause more than one third of inappropriate shocks to younger individuals. Younger patients might not have the same physical limitations as older individuals such as restrictions due to heart failure. They are likely to be more active and engage in more physical activity. This increased activity, though, might cause younger individuals to unintentionally damage their leads. Cardiac device leads have been the root cause of many complications. The device can deliver inappropriate shocks, but the device could also fail to deliver necessary, life-saving shocks due to malfunction. Fortunately, wireless remote monitoring can help patients detect lead failure prior to cardiac episodes. Again, lead failure is higher in younger, more active individuals (Sherrid & Daubert, 2008).

Another risk is that an individual might have the ICD implanted, but the device may never have to administer a shock. The severity of the medical condition and potential for heart failure is weighed against the risks of implantation. Younger individuals must take time off from work for re-implantation and allow for recovery time. Further considerations include the costs of the device, procedure, and follow-ups. For these individuals, the ICD serves as a safety net. For young individuals, facing the decision to receive an ICD implantation can be a lifelong decision. This makes patient education and informed consent particularly important for this population. The physician is responsible for ensuring that the patient and family are well informed of the risks, benefits, and options available due to the permanency of sudden death and sudden cardiac arrest (Sherrid & Daubert, 2008).

Quality of Life and Psychological Well-being

Younger ICD recipients, 13-40 years old, are able to return to school, or work, with minimal limitations. However, these recipients might experience more psychosocial stress than their peers. A study by Vitale and Funk (1995) indicated that young participants with an ICD reported good health as well as adjustment problems. These problems included worry about or avoidance of physical activity,

sexual activity, concerns with body image, and social interactions. Participants reported increased death anxiety and fear of the device shocking them. Participants also reported social isolation and limited physical activity due to the ICD (Vitale & Funk, 1995).

In a study by Webster et al. (2014), researchers explored the psychiatric functioning and quality of life for children and adolescents with cardiac rhythm devices (Webster et al., 2014). Participants were recruited from Boston Children's Hospital. The sample included a total of 166 participants between the ages of 6 and 20 years old (median = 15 years old). Only 52 participants, 31%, were ICD recipients. The rest of the sample lived with a pacemaker. All of the participants had their first ICD or pacemaker implanted within six months of the study's start. Compared to the participants with pacemakers, the ICD recipients used in this study were on more medications, had a higher prevalence of family heart disease, and had more restrictions on activity.

Psychiatric interviews were conducted with each participant and self-report questionnaires were administered to the participants and their parents. The measures used in this study included the Device Severity Index (DSI); Schedule for Affective Disorders and Schizophrenia in School Aged Children and Adolescents - Present and Lifetime Version (K-SADS-PL); Revised Children's Manifest Anxiety Scale, Version 2 (RCMAS); Reynold's Child Depression Scale; Reynold's Adolescent Depression Scale; The University of California, Los Angeles Posttraumatic Stress Disorder Reaction Index; Child Health Questionnaire-50; Impact on Family Scale (IFS); and the Brief Symptom Inventory (BSI).

The findings indicated that individuals with an ICD experienced more anxiety and depression than a healthy population ($p < 0.1$). Both ICD and pacemaker recipients had similar levels of depression compared to healthy controls. Among the participants with an ICD, there was a higher prevalence of anxiety or depressive disorders compared to participants with a pacemaker (27% vs 11%, $p = 0.02$). Both ICD and pacemaker recipients reported a lower physical quality of life compared to a healthy population ($p \leq 0.03$) (Webster et al., 2014).

The study indicated a prevalence of anxiety among the participants. However, it should be noted that the results might be attributed to other underlying medical conditions or the age of the child. Participants with an ICD or cardiac device implanted at an older age were more prone to perceive the ICD

as an intrusion. In comparison, younger patients with ICDs became adapted to living with the device due to early placement (Webster et al., 2014). The study primarily looked at anxiety and depressive symptoms. Other psychiatric disorders, including neurological, were not assessed in this study. The study also did not take into account socioeconomic status.

Sossong (2017) conducted a descriptive correlational study that examined whether knowledge about ICDs and uncertainty could predict quality of life. Ninety patients with ICDs, between the ages of 36 and 88 ($M = 65$ years old), were recruited from a rural hospital. Most of them were white, male, and retired. The mean length of time of ICD implantation was about 15 months. Most participants needed an ICD implanted due to ventricular tachycardia (86.67%). The Sossong Implantable Cardioverter Defibrillator Knowledge Questionnaire (SICDKQ) was used to assess general ICD knowledge. The Mishel Uncertainty in Illness Scale (MUIS-Adult or MUIS-A) was used to assess uncertainty. Ferrans and Powers Quality of Life Index - Cardiac Version IV was used to assess quality of life.

Overall, participants reported a high level of uncertainty. In general, participants were satisfied with their quality of life and reported high ICD knowledge. Younger participants, however, reported a lower quality of life. The researcher thought this result might be due to differences in perceived locus of control. Older individuals typically have a stronger sense of self, clearer goals and values, and an internal locus of control (Sossong, 2017). Sossong's findings are congruent with those of Bainger and Fernsler (1995) who observed that young ICD recipients in their study, who are unemployed, appeared to be at higher risk for health issues than older ICD recipients.

ICD recipients who have experienced a shock from the device are also more likely to experience depressive symptoms. Those who have experienced repeated shocks have an increased risk of developing these symptoms. Possible factors that impact the development of these symptoms include positivity, support, and attachment style (Jacq et al., 2009). Anxiety, depression, anger, and fear are commonly experienced following ICD placement (Dunbar, 2005). ICDs can administer inappropriate shocks to the patient. Moreover, this can happen when the individual is conscious. Other concerns include malfunctions of the device, the impact of cognition, the ability to drive, and physical restrictions. Psychosocial symptoms, including depression, anxiety and post-traumatic stress, can contribute to poor

compliance with medical recommendations. Individuals experiencing these symptoms are more likely to engage in smoking, physical inactivity, or other unhealthy behaviors (Ingles, Sarina, Kasparian, & Semsarian, 2013).

In order to get a more emic understanding of ICD patients' experiences, Italian researchers Garrino, Borraccino, Peraudo, Bobbio, and Dimonte (2018) conducted a qualitative study of participants recruited from an Intensive Care Unit. Patients that met criteria were contacted by telephone. Of the 20 participants, 8 were between 40-50 years old, two participants were younger, and the rest of the participants were over 50 years old. The median time since the initial ICD implantation was about 4 years. Most participants were retired. The participants engaged in a semi-structured one-on-one interview with a registered nurse.

The study revealed four main themes: living with fear, relying on technology, knowing about the ICD and how to live with it, and coping with the effects of the ICD on everyday life. The study indicated that living with an ICD causes feelings of anxiety. The participants experienced fears in their everyday life that negatively impacted their overall quality of life. Participants indicated that they felt like they received enough information about the technical aspects of their device, but did not have adequate information regarding how the ICD would impact their daily lives. Some individuals felt like they were not provided information on what to expect mentally or physically or what was considered normal with regard to ICD shocks. The younger participants in particular expressed concern over this lack of information. Younger participants also reported more anger and depression than older participants. The participants expressed anger toward their underlying heart condition and the unexpected impact it had on their lives (Garrino et al., 2018).

A recent comprehensive review of literature conducted by Pyngottu, Werner, Lehmann, and Balmer (2019) on health-related quality of life and psychological adjustment among children and adolescents living with ICDs and pacemakers indicated a lower health-related quality of life compared to their healthy peers. Health-related quality of life was assessed on the basis of how people perceive the impact of their health, disease, treatment and its consequences on physiological, psychological, social functioning and well-being. The study indicated that individuals with an ICD were more affected by anxiety

than individuals with a pacemaker. Medical diagnosis and severity, and age of implantation might influence this as well (Pyngottu, Werner, Lehmann, & Balmer, 2019).

Sudden cardiac arrest is a complication of genetic heart disease. Much research has focused on older individuals with ICDs who often suffer from heart failure or myocardial infraction. Genetic heart disease, if found in younger individuals, is frequently asymptomatic. These individuals have the stress of potential inheritance risk, genetic testing, lifestyle modifications, long-term medical monitoring, restricted physical activity and sudden cardiac arrest risk (Ingles et al., 2013).

Ingles et al. (2013) conducted a quantitative study in Australia exploring the psychological impact of ICDs on young adults diagnosed with genetic heart disease. The participants, recruited from the Australian Genetic Heart Disease Registry, had to meet the following inclusion criteria: be at least 15 years old and have an ICD implanted at least a year prior to their participation in the study. Participants also needed to have a diagnosis of inherited cardiomyopathy, primary arrhythmogenic disorder, and other genetic heart diseases. The mean age of participants was 49 years old and the mean age of ICD implantation was 45 years old. The mean length of ICD implantation was five years. Eligible participants were sent information, a consent form, and surveys via mail. Participants provided information on ICD shocks and responded to open-ended questions. The participants also completed the Hospital Anxiety and Depression Scale (HADS) and the Impact of Events Scaled-Revised (IES-R).

The results indicated higher levels of anxiety in female participants. Fifty-percent of female participants reported significant symptoms of posttraumatic stress compared 13% of male participants ($p = 0.05$). Overall, participants indicated psychosocial scores within normal ranges. However, some participants indicated significant levels of anxiety (38%), depression (17%) and posttraumatic stress (31%) (Ingles et al., 2013). Only 65% of individuals approached to participate in the study responded. A follow-up with participants who chose not to respond could provide useful information to inform future studies. It is possible that individuals that are less open discussing and addressing psychosocial issues related to living with an ICD are more prone to experiencing psychological symptoms.

Individuals that experience a cardiac arrest and anoxic injury to the brain are more likely to experience more psychosocial problems. A quantitative study by Wilson et al. (2014) explored the

psychosocial outcomes of individuals who experienced anoxic brain injury following a cardiac arrest. Fifty-six individuals, 27 with anoxia and 29 without anoxia, participated in the study. Their participation occurred between six months and four years following their cardiac arrest. All participants were over the age of 18 years and had been treated with an ICD. Individuals with a diagnosis or history of neuropsychological dysfunction were also excluded from the study.

Participants who experienced anoxia indicated more problems with social functioning than the non-anoxic group. Some of these difficulties might be attributed to the memory and executive functioning difficulties associated with anoxia. The higher levels of anxiety and depressive symptoms might be a consequence of sustained neurological damage. Anxiety is typically associated with the hippocampus and pre-frontal cortex. Depression is associated with the basal ganglia and the left frontal areas. These areas of the brain are susceptible to damage with anoxia (Wilson et al., 2014).

Bremer, Dahlberg, and Sandman (2009) did a qualitative, descriptive study in Sweden on the search for meaning following an out-of-hospital cardiac arrest. The study used eight men and one woman between the ages of 44 and 77 years old. Seven of the participants contacted the researchers after reading an article in the newspaper regarding the study. The other two participants were found using *The National Register of Out-of-Hospital Arrests*. The time between the cardiac arrest and the interview was anywhere between six months and 15 years. All cardiac arrests were witnessed by at least one bystander. All of the participants had an ICD implanted as secondary prevention.

One of the common topics participants discussed was the experience of waking up from the cardiac arrest and feeling uncertain. The memories of the event and following the event are a blur and fragmented. The participants experienced a loss of coherence in their memories and were reliant on others to fill in the gap. The event itself is difficult for the individual to grasp. The concept of being on the verge of death and the unknown can leave the individual with some anxiety. Some participants also experienced feelings of guilt regarding their lifestyle before the cardiac arrest and how they might have contributed to the cardiac event. On the other hand, participants also expressed a sense of gratitude, especially considering the small percentage of people that survive out-of-hospital cardiac arrests. Participants further experienced existential death anxiety. The fragility and uncertainty of life became

more evident following participants' brushes with death. There was an underlying diffidence about why the cardiac arrest happened and why they survived. Individuals might have become more insecure about their bodies and their function. For some individuals, an ICD also can be a constant reminder of the failure to their bodies and the possibility for another cardiac arrest. Deeper understanding of the body can mitigate some anxiety for some individuals (Bremer, Dahlberg, & Sandman, 2009).

Similar themes were discovered in a study by Dickerson (2002). The method used in this study involved secondary analysis of transcripts of individuals who experienced sudden cardiac arrest and had an ICD implanted. Secondary analysis used an existing data set to develop areas that were not specifically addressed in the original study and to answer queries that were not previously addressed. The data used included analysis of interviews with 62 individuals.

The major themes that emerged in the study included the following: *losing control*, *regaining control*, and *creating a new vision for life*. Some individuals fear being alone due to uncertainty of whether or not the device would work and fear of being shocked. Not only does an individual lose control when they experience a cardiac arrest, but an ICD implantation requires one to relinquish control, too. Although individuals in the study cognitively realized the importance of an ICD, they reported that they struggled to accept the device (Dickerson, 2002). Another common theme was the process of returning to a sense of the regularity in their lives. Depending on the frequency of shocks and their medical condition, this was more challenging for some. These individuals have had to make adjustments, to varying degrees, in how they continue to live their lives. Research about one's condition and ICD and in-person and online support groups were ways that people coped with living with an ICD and the looming fear of another cardiac episode (Dickerson, 2002).

The study also addressed the topic of getting the ICD battery changed. The experience of living with an ICD might be more stress-inducing than living without a device for some individuals. Depending on the limitations of living with the device, they might have to sacrifice certain dreams and aspirations. One man in the study spoke about a dream to retire and play golf, but his limitations did not allow him to do this. These types of adjustments and sacrifices can be difficult to come to terms with. Over time, these

individuals are able to find value in their life post cardiac arrest. It can be a transformative experience for some that impacts their perspective, worldview, and meaning of life (Dickerson, 2002).

McDonough (2009) did a qualitative study on young adults, between 18-40 years old, with ICDs. The purpose of the study was to gain insight into the experience of young adults living with an ICD. The participants were recruited from ZapLife.org and from an ICD clinic in Boston. The study did internet and phone interviews with 20 participants. The mean age of participants was 34 years old and about two-thirds of the participants were married and working. There were 12 females and eight males that participated in the study. The participants were also predominately Caucasian. Many participants (55%) were diagnosed with hypertrophic cardiomyopathy (HCM). Others had dilated cardiomyopathy (10%), Long QT Syndrome (LQTS) (10%), and idiopathic ventricular tachycardia or ventricular fibrillation (25%). The average length of time since implantation was about four years. The main theme discovered across interviews was a transition to a new normal. Subthemes found in the study included anxiety and concern after initial diagnosis and learning that they needed an ICD, caution performing activities, passing a cardiac disease to their children, a sense of security provided by the ICD, financial concerns regarding replacement and maintenance of ICD, and physiological and psychological issues.

Following implantation, participants expressed feelings of anger, resentment, depression, and fear, as well as issues with body image. The young adults in this study indicated issues different from older adults. This included marriage, family planning, and occupation. Many of the participants in the study participated in sport activities. Some had to make adjustments and chose to participate in lighter activities, but many remained physically active. Similar to older and younger ICD recipients, participants in this study also expressed feelings of anxiety and fear of the device firing. Participants also found that time helped make living with an ICD easier as they began to find a new normal. The participants in the study indicated that joining online support groups, sharing their story, using social support, and focusing on positive aspects of life helped minimize any negative impact of adjusting to living with an ICD. Providing information and educating family and friends about the ICD was another way that participants felt more in control of their lives (McDonough, 2009).

A qualitative study in Australia (Williams, Young, Nikoletti, & McRae, 2007) interviewed 11 individuals with an ICD, ages 30-80, and 11 caregivers. The ICD recipients consisted of eight males and three females. Four participants had the ICD for < 2 years, two lived with an ICD for >3 years, and five of the participants lived with an ICD for 2-3 years. The article did not provide demographic information for the participants. A major theme found in the study was the concept of *getting on with it*. This meant accepting the ICD and moving forward. The ways participants did this was by going back to work or resuming daily routines, positive interpretations of living with an ICD, reassessing lifestyle and making changes, trying not think about the ICD and assessing their own capabilities rather than relying on what they were told (Williams et al., 2007). Although the study provides valuable information, the study does not indicate the mean age for the participant sample. The large age range makes the generalizability of the study's findings more limited. It is likely that obstacles with moving forward and accepting living with an ICD differ between older and younger recipients. Also, the article does not specify the underlying cardiac diagnosis of the participants.

More than half of ICD recipients are men (Jakub, 2018). One qualitative study explored the influence of age and gender on the adjustment of male ICD recipients. Eleven men participated in the study. The participants lived with an ICD for at least four years and had at least one re-implantation. The reason for ICD implantation varied among participants. Ages of participants ranged from 26-85 years old. Participants were observed by the researcher during their ICD interrogation from a separate room. Then participants engaged in semi-structured interviews. Maintaining a masculine image, sudden cardiac death, and social implications through time and self-image influenced by chronic illness were identified as themes in the study. The participants in the study were determined to maintain their independence and resume a normal life with minimal restrictions. The older participants (40-65 years old) in the study reported more acceptance of the device than younger participants.

Near-Death Experiences

Near-death experiences, such as cardiac arrests, can be described as visual experiences or recollections that occur during the period of unconsciousness. Other experiences might include a car accident or other instances in which an individual thought he or she was about to die. These visions, often

depicted in movies, might include seeing bright lights or going through a tunnel (Cant, Cooper, Chung, & O'Connor, 2012). Some might also have an out-of-body experience, meet dead relatives, or even experience their life in a glance (Van Lommel, 2011).

It is possible that these experiences are due to the physiological impact of these events on the brain. Anoxia, or an anoxic brain injury, occurs when there is a decrease in blood flow or oxygen to the brain (Ferri, 2018). High levels of carbon dioxide in the body is another explanation. A study by Klemenc-Ketis, Kersnik, and Grmec (2010) showed that 21% of the study's 52 participants who reported an out-of-hospital cardiac arrest also experienced a near-death experience. One correlation discovered in the study was higher amounts of carbon dioxide in these individuals (Klemenc-Ketis et al., 2010). However, research has yet to discover why only a small percentage of patients that experience anoxia and high levels of carbon dioxide have a near death experience.

A study by Van Lommel et al. (2001) surveyed 10 different Dutch hospitals and 344 patients that survived a cardiac arrest. Eighteen percent of the participants reported a near-death experience. A majority of these individuals were older. Common near-death experiences reported included the following: a feeling of peace, having an out-of-body experience, or a paranormal experience. Following near-death experiences, individuals reported changes in beliefs, fear of death, and having an easier time managing stress. Due to the difficulty in obtaining data, this is an under researched area. However, brain imaging has indicated that an increase in frontal lobe functioning and decreased activity in parietal lobe have been linked to paranormal experiences. It has been shown that similar experiences have been reported with procedures for epileptic patients in which there is electrical stimulation of the temporal lobe. The hippocampus is located in the temporal lobe and is the part of the brain responsible for the regulation of emotion. It is also associated with memory. However, if physiological factors and changes in the brain are the contributing factors to these experiences, then more of the participants should have had near-death experiences (Van Lommel et al., 2001).

Mental Health

Psychological treatment for individuals with ICDs can help improve their quality of life. ICD education can be beneficial, especially if a patient holds false beliefs about the device which contribute to

fear or feelings of sadness. Discussing and walking through situations, like getting through security at an airport, might ease the amount of distress the person experiences. Increased understanding of one's heart condition, normalizing concerns, and processing the adjustment to living with the device can also minimize his or her fears (Sears et al., 2004).

Cardiac disorders can lead to increased levels of anxiety. ICD implantation can lead to a reduction of this anxiety for some. On the other hand, preexisting anxiety can also be enhanced following the implantation. These individuals are more likely to interpret bodily signals as threats. It is also likely that those who experience catastrophic thinking and interpretations have higher levels of anxiety and depression (Pauli et al., 1999). Individuals might keep track of the number of shocks they experience, which might be referred to as a *sickness scoreboard*. The number of shocks might be seen as indicator of health to these individuals. This can be beneficial to those not receiving shocks, but not for those that receive frequent shocks. This idea is proposed in the cognitive appraisal theory of ICD activity (Sears et al., 2004).

Other theories have been posed to explain psychological adjustment in individuals who have experienced ICD shock. The learned helplessness theory posits that those who feel like they have no control develop feelings of hopelessness and depression regarding their health. Some individuals might associate environments and behaviors with times they have received shocks. Classical conditioning theory indicates that this pairing can lead to the development of fear or arousal (Sears & Conti, 2003).

Cognitive behavioral therapy might be more successful in these individuals and can help challenge and change catastrophic thinking. Emphasizing the positive, life-saving aspects of the device and developing a more positive outlook on the device can be addressed by cognitive behavioral therapy. Family therapy can assist families of individuals with an ICD to address topics including changes in roles, lifestyle, and sexual health. The implantation not only impacts the patient, but the family as well (Sears et al., 2004).

Diaphragmatic breathing, progressive muscle relaxation, and imagery can assist alleviate feelings of anxiety. Those who have experienced shocks might develop a tendency to avoid situations in which they've received shocks. Exposure therapy might be a useful technique to overcome the underlying

anxiety. The complex nature of underlying medical conditions of these individuals makes it important for therapists to collaborate with the treating physician. It is helpful for the therapist to be aware of any restrictions, recommended activity level in order for the therapist to collaborate with the patient in developing realistic goals (Sears et al., 2004).

A qualitative study conducted by Dickerson, Posluszny, and Kennedy (2000) examined the effectiveness of support groups of individuals with an ICD. The study took place over nine months and involved people that were attending a support group for individuals with ICDs and their support persons. The participants in the study included 15 individuals with ICDs and nine support persons. Data was collected using 5 focus groups and 7 individual interviews. The article did not clarify whether support persons were spouses, adult children, or hired support.

The support group, facilitated by a clinical nurse specialist, met monthly at the hospital for one hour. The average number of attendees was typically between 15 and 20 people. Participants had been attending the support group from two months to five years. The mean length of attendance was 1.6 years. Not all group members attended on a regular basis. The mean age of participants was 65 years old with participants ranging from 40 to 76 years old. Thirteen of the participants experienced sudden cardiac arrest. The mean number of ICD firings was six. Themes that emerged from the study included hearing and telling stories, seeking meaningful information, forming a therapeutic alliance through group companionship, assistance from the facilitator, sharing a similar view with other group members, and seeking help.

The support group helped validate the feelings of the group members. Members of the group found advice from others with an ICD to be more reliable and credible due to shared experiences. It was also comforting to hear other members talk about similar experiences living with an ICD. Discussing fears helped members gain more hope because they heard about how others were coping with their problems. Participants also expressed feelings of warmth from other members of the group and a feeling of altruism by sharing their own experiences with others. Many conversations dealt with coping with daily stressors. This included traveling, health insurance, and integrating information from health providers. It was helpful to have an open forum to discuss disagreements or issues with health providers (Dickerson, Posluszny, &

Kennedy, 2000). Support groups for individuals with ICDs provide a good source of information, validation and support to help cope living with an ICD. Further research might address the effectiveness of a group run by a health care specialist compared to groups that do not have a professional facilitator.

A pilot study examining the efficacy of a Mindfulness Based Stress Reduction (MBSR) program for adolescents with ICDs or pacemakers showed decreased levels of anxiety in its participants. The MBSR program consisted of psychoeducation, meditation, yoga, and group support. The study used 10 participants between 12-18 years old. The participants completed the Hospital Anxiety and Depression scale and Responses to Stress Questionnaire at the outset of the program and at the sixth and final session. Coping strategies learned during the program likely contributed to the decrease in anxiety and depressive symptoms reported (Freedenberg, Thomas, & Friedmann, 2015).

Sotile and Sears (1999) suggest the use of a checklist to help providers identify and manage psychosocial issues of individuals with ICDs. They called it *The Four A's Checklist*. The four A's are ask, advise, assist, and arrange. The first step is to *ask* patients about issues related to their ICD. For young adults, issues to ask about might include peer relationships, emotional stability, cognitive functioning, and comparison to other regarding abilities and limitations. This can give a provider more information on the patient's overall adjustment to living with an ICD (Sotile & Sears, 1999). However, weak rapport between the patient and provider may prevent the patient from sharing issues he or she is facing. Providers also might not be comfortable discussing these topics with their ICD patients.

The second step is to *advise* the patient on challenges related to living with an ICD and how to address these concerns. The provider can then *assist* the patient by focusing on immediate issues. This might include providing more education on the patient's device or help problem solving. However, there may be issues that arise that are outside the provider's area of expertise. The final step is to *arrange* consultations for individuals who might benefit from speaking to a mental health provider (Sotile & Sears, 1999).

The article also mention that young ICD recipients might benefit from connecting with another ICD recipient, or an *ICD Buddy*. This would assist with issues of social comparison and provide additional social support (Sotile & Sears, 1999). However, connecting young individuals with other individuals with

an ICD might be difficult due to the small number of young ICD recipients. Although the article provides useful strategies for providers to use, there has not been a follow up study on the effectiveness of *The Four A's Checklist* in reducing stress in young ICD recipients.

A study by Sears et al. (2000) surveyed health care providers' perceptions of ICD recipients' quality of life and psychosocial functioning, concerns or issues reported by ICD patients, and the degree of comfort managing concerns of individuals with an ICD. The participants included 103 physicians and 157 other health care professionals. Most of the physicians were electrophysiologists. The other health care professionals primarily consisted of nurses and physicians' assistants. The results of the study indicated that participants felt less comfortable addressing ICD recipients' emotional and psychological concerns over other lifestyle issues.

Another study discovered that communication between patients and physicians was an area of stress (Linder et al., 2013). Participants in the study reported wanting to have more discussion with their provider prior to having the ICD implanted. Participants who did not feel like they had ample discussion prior to implantation indicated more complications. In cases where immediate implantation was necessary, family members wanted to be more informed about why the device was necessary for the recipient. It varied amongst participants whether or not they were adequately informed.

Posttraumatic Growth

Posttraumatic growth is a process in which individuals experience positive personal growth following a significant life-changing event or situation. There are five factors that are included in posttraumatic growth: relating to others, new possibilities, personal strength, spiritual change, and appreciation of life (Zeligaman, Varney, Grad, & Huffstead, 2018). Individuals suffering from chronic illnesses, such as cancer survivors, indicate posttraumatic growth.

There are both emotional and physical benefits of posttraumatic growth. One quantitative study assessed social support and meaning making in a sample of adults living with chronic illness. The results indicated that social support was a predictive factor of posttraumatic growth. The meaning of life individuals create due to social relationships are indicated to be more important than the relationships themselves (Zeligaman et al., 2018).

Summary

ICDs are life-saving devices for individuals at risk for sudden cardiac arrest. In addition to the physical risks, these individuals are at risk for developing psychological symptoms including depression, anxiety, posttraumatic stress, and guilt. There has been both qualitative and quantitative studies demonstrating the challenges that ICD recipients face. Studies sometimes group ICD and pacemaker recipients together which makes it difficult to pinpoint ICD-specific challenges. The fear of being shocked by an ICD presents a unique challenge for ICD recipients. Many studies discussed above have used a sample with a broad age range and a limited sample. This is likely due to the difficulty of finding participants that are willing to participate in a study of such a personal nature. Many of the studies are done in countries outside the United States. The experience of ICD recipients in other countries might be different from those in the United States, especially considering differences among health care systems.

Given the limited research on individuals with an ICD placement, particularly younger individuals, this study aims to further understand the experience of these individuals. It is important for the medical community to understand the experience, the psychosocial stress and resilience of these individuals in order to build awareness and provide the necessary support and treatment. This will also provide insight to families and friends of someone living with an ICD and underlying cardiac complications. Moreover, this study also aims to normalize the experiences of a person with an ICD.

Statement of the Problem

The statement of the problem is the rationale statement for the study. It underscores the study's importance (Rossman & Rallis, 2017). The statement of the problem provides the reasoning behind the study. It identifies a significant gap in the research, especially one that has serious consequences for those whose experiences and perspectives have been marginalized in the extant literature. The researcher proposes an inquiry that will add to the knowledge base and address the negative impacts of the current omissions (Marshall & Rossman, 1999). The rationale also provides readers with a frame of reference for why they are doing the study- often an ethical reason for conducting the study to address the omission (Rossman & Rallis, 2012).

The current literature indicates increased depression and anxiety among individuals with an ICD. The anxiety and depressive symptoms associated with an ICD can lead individuals to develop serious mental health concerns. Despite these emergent findings, there is limited research on the mental health concerns of individuals with ICDs and their experience, particularly among young adults (Sears et al., 2004; Van Lommel et al., 2001).

Purpose of the Study

The statement of purpose explains the intent of the study, its specific goals, and utility. It frames the study and provides the focus and aim of the study. It identifies the phenomenon of interest, the nature of the study, the specific methodology that will be used, relevant definitions, and the unit of analysis (Creswell, as cited in Rossman & Rallis, 2017). The statement of purpose can be helpful to the researcher as she enters and immerses into the field. It is a reminder of the study's focus and will assist him in forming suitable questions for the interview. Having a statement of purpose can also assist the reader in gaining a clear understanding of the aim of and proposed approach to the study (Glesne, 2016).

The purpose of this study is to describe and explore a young individual's experiences of living with an ICD using a transcendental phenomenological design. The result will be in a discussion of themes and patterns. An *ICD* is provisionally defined as a life-saving device for individuals with ventricular arrhythmias and those at risk for sudden cardiac arrest, pending exploration of the participant's own personal understanding of what an ICD is (American Heart Association, 2016).

Research Questions

Research questions are the questions that the researcher wants to be answered by the study. Research questions help pinpoint the overall idea of the study and helps to focus the area being explored. These questions also help provide some boundaries for the study. The types of questions used to guide a qualitative inquiry are open-ended and non-directional. They focus on perceptions, meanings, and process (Glesne, 2016).

The four categories of questions used to guide a phenomenological inquiry are descriptive, experiential, process, and meaning questions (Moustakas, 1994). Descriptive questions look at the nature of the phenomenon being studied. Experiential questions seek a better understanding of the participants'

perceptions and meaning construction of the experiences surrounding the phenomenon. Process questions are used to discover how the phenomenon changes over time and how its meaning evolves. Meaning questions are used to find out the significance attributed to the phenomenon by those with direct experience of the phenomenon.

The main questions asked in this study include:

- (1) What is the nature of having an ICD?
- (2) What is the experience of having an ICD?
- (3) How does the experience of having an ICD change over time?
- (4) What is the meaning of living with an ICD for a young adult?

Grand Tour Questions

Grand tour questions are open-ended questions that are asked in order to gain a greater depth of understanding of a participant's experiences of a phenomenon. They are conversational questions the researcher asks the participants. These questions attempt to capture the feelings, thoughts, beliefs, and behaviors surrounding the participant's experience during focused conversation (Rubin & Rubin, 2005). Grand tour questions inspire participants to direct the interview and provide the interviewer with a "tour" of their experience regarding the phenomenon being explored. This allows the participant rather than researcher lead the inquiry over time. These questions prompt more narrative exploration of a phenomenon.

The proposed initial grand tour questions for this study include:

- (1) What led you to get an ICD?
- (2) Describe your life before getting an ICD.
- (3) Tell me about the stress you have experienced with your ICD?
- (4) Tell me about the stress relief or benefits you have experienced with your ICD?
- (5) Describe a time recently when you got stressed. What did you do?

Significance of the Study

The significance of a study is a statement outlining the aspirations of the researcher in conducting the study. In a qualitative study, it also points out who might benefit from the study and identifies the

different stakeholders. This practical component helps enhance the study's moral praxis and utility. By identifying potential stakeholders and considering how they might benefit from the study's findings, the researcher has an opportunity to consider ways in which the study can explore aspects of the phenomenon that go beyond the researcher's interests (Glesne, 2016).

This study will be beneficial to those with an ICD placement and expand their awareness of the experiences of their peers. This will be especially beneficial due to the small number of young individuals living with an ICD. It could create some normalcy in shared experiences. It also may benefit the family members and friends, providing them with more insight into the challenges and stressors that individuals with an ICD experiences. Replication of this study may further add to the knowledge base of this phenomenon as experienced by different age groups.

This study and future studies may prove beneficial for health care providers, including electrophysiologists and psychologists, to incorporate ways to address the mental health concerns of those living with an ICD. Ample awareness and proper support and services can lead to decreased psychosocial symptoms experienced by these individuals with an ICD.

CHAPTER II. APPROACH

[The following chapter is written in the future tense. It documents what I propose to do in the field.

Chapter III, which follows, documents the actual field methodology as carried out during the study.

Presenting the proposed and actual approach allows for methodological transparency. Any major changes to the structure of the approach indicated in the proposed field methodology will be documented and cleared by my CRP committee and the Chaminade University of Honolulu Hawai'i Institutional Review Board (IRB).]

Rationale for Use of Qualitative Methodology

Qualitative inquiry is a method of research that focuses on finding meaning and understanding of subjects that are not understood. This method attempts to gain a deeper understanding of these subjects through the examination of small, non-random samples of critical cases that exemplify the robustness of a phenomenological experience. By interviewing those with richer, more intimate lived experiences of a phenomenon, researchers inductively build and refine theories (Wertz, 2011).

The four main uses of qualitative inquiry findings include: instrumental, enlightened, symbolic, and transformative/emancipatory uses (Rossman & Rallis, 2017). Qualitative findings can be used instrumentally to help solve practical problems. Enlightened uses involve building theory and beginning analysis of unknown phenomena. Symbolic uses involve gaining understanding of nuances and a new understanding of familiar areas of study. Transformative/emancipatory uses of qualitative research include transformation of aspects of society, exploring what shapes people's views of reality and truth, or looking at underserved communities.

The study I am proposing to conduct reflects the instrumental and enlightenment uses of qualitative inquiry. The information gathered from the study aims to enhance awareness to the experiences of a young individual living with an ICD. This information can then be used to inform future studies of health care practices that explore ways to address the mental health of these patients more meaningfully. The study will also work toward uncovering a more emic understanding of the experiences of those more affected by ICD technology, giving them a voice in their care.

Specific Methodology

Transcendental phenomenological method is a postmodern version of traditional phenomenological methodology. It places more emphasis on bracketing or the process of *epoché*; managing researcher biases. It uses a semi-structured rather than structured interview protocol and explores what and how people experience a phenomenon. It requires the researcher to minimize biases and move beyond interpreting the data from a more etic perspective. It seeks to present the findings from the participant's emic perspective (Moustakas, 1994).

This proposed study will use semi-structured interviews to capture the story of an individual's unique experience of living with an ICD. Three interview sessions will be held with the participant to uncover key themes from his or her experiences. The fourth meeting will be to share with the participant what I think I have understood from our previous meetings. I will provide the participant the opportunity to check the accuracy of my write-up representing the participant's narrative. The participant will be able to make any edits or changes in how his or her experience is represented. I will analyze the themes that emerge from the interviews and create an integrated narrative. During our fourth meeting, I would like the participant to make changes to the final integrated narrative as well. I will also like to take time to discuss the participant's experience of the interview process.

This method of research seems more appropriate than using a quantitative method in an attempt to explore and capture the emic experiences of an individual with an ICD. Transcendental phenomenological method would allow for a greater understanding of the experiences of a person living with an ICD. I think it is a complex topic that can be better explored and captured through a narrative and thematic process that can uncover the unique, nuanced experiences people can have when dealing with an implanted medical device and underlying medical concerns. A statistical approach might identify what might be average to a group but it would fail to portray the breadth and depth of experiences associated with the same phenomenon across members of a group.

Role of the Researcher

Intersubjectivity

The interpretivist or qualitative paradigm assumes that reality is socially constructed and intersubjective. In other words, the participant and the researcher have an impact on another and the subjectivities of each are difficult to separate (Glesne, 2016). Paradoxically, the intent of qualitative research is to capture the subjective experiences of the participant. This requires the researchers to minimize his or her impact on the narrative of the participant as much as possible. To do so, the qualitative researcher usually uses participant observation, a process of moving along a continuum between pure participant and pure observer in order to gain an understanding of the phenomenon from multiple vantage points (Glesne, 2016).

Participant Observation

In qualitative research, the researcher is both a participant and observer. The researcher moves along a continuum between full participant and full observer, going between being engaged and being detached. It is a little bit of a dance going back and forth between full participant and full observer. Through this process, the researcher is able to gain a better understanding and capture more of the participant's story by participating while maintaining some perspective. Being more of a participant allows the researcher to best capture the participant's lived experience and its core meaning. It provides the researcher with a closer understanding and grasp of the phenomenon being explored. With participating, though, there is the risk of becoming too immersed in the study and *going native*. A researcher that goes native believes that he or she is part of the group he or she is researching and is in the know. He or she becomes less curious and may make assumptions that are incongruent with the authentic experience of participants. The advantage of being an observer is that the researcher is able to maintain some perspective by remaining relatively uninvolved. However, if the distance between the observer and participants becomes too great, it can limit the researchers access to the emic experience of the participant (Glesne, 2016).

Ethical Considerations

The four categories of ethical theory that are used to inform qualitative inquiries include theories of consequences, rights and responsibilities, social justice, and care (Rossman & Rallis, 2017).

Consequentialist theories focus on outcomes and are geared toward making decisions that will benefit the greatest number of people. Nonconsequentialist theories include ethical theories of rights and responsibilities and focus on the inherent worth and respect of individuals and importance of protecting their innate rights. Ethical theories of justice, which include critical ethics, rely on a belief in fairness to determine which actions are right or wrong. Qualitative research informed by an awareness of social inequities manifest in certain phenomena can be used to inform consumers of research by investigating the history and impact of these inequities. This can have an emancipatory effect and shape social aspects of the world by shedding light on oppressive structures or underserved communities (Rossman & Rallis, 2013). Ethics of care focus on concrete situations rather than principles. Covenantal ethics, for example, place an emphasis on the relationship between researcher and participants and emphasize respect and fidelity (Glesne, 2016). This is particularly important for qualitative researchers. The relationship developed between the researcher and participant should be based on collaboration and a joint ownership of the results of a study.

While all four categories of ethical theories are used to address ethical dilemmas encountered in the field, critical and covenantal ethics are especially important in informing the nature of the relationship between the researcher and her participants. A qualitative researcher has to be able to manage power differentials when dealing with participants, especially participants who belong to marginalized communities. The researcher also has to be conscious of the environment in which she is conducting research and the implications the study might have for people actively engaged in the phenomenon of interest.

Informed Consent

An important aspect of an ethical study is its ability to provide informed consent. The participant has to know what is being asked of him or her in order to make a decision to participate and what to

disclose. The informed consent also discusses the risks and benefits of participation, confidentiality and anonymity.

The participant further needs to know that he or she is allowed to withdrawal from the study at any time without being required to state a reason for withdrawal or being concerned about negative consequences from the researcher. Moreover, the participant is not required to answer all questions asked of them. He or she may also elect to pass on questions and answer them at a later time. The participant may further choose to speak off the record at times; with the audio recorder turned off and only turned on again only when he or she is ready to speak on the record. Anything discussed when the audio recorder is turned off will not be included in the data base for the study unless the participant chooses to discuss the same information on the record later in the study. The clearer the researcher is about participating in the study and the study's aim, the more comfortable the participant can be in making a decision. This also fosters trust between the participant and the researcher (Glesne, 2016).

Interpretive Authority, Voice, and Ownership

Interpretive authority holds that the participant has the right to self-determination in the telling of his or her story; the participant has final say in how the data will be presented. Thus, when a draft of the participant's narrative is completed, the participant will have a chance to review it and make any additions, deletions, and edits that will make the narrative more accurate with respect to the participant's interpretations of his or her experiences. The participant will also be asked to review exemplar quotes the researcher would like to use to illustrate the themes in the narrative. This review is completed before completing the final informed consent and release of information protocol that grants the researcher permission to enter the narrative with exemplar quotes into the data for the study. Since the researcher is portraying a personal experience, the presentation of the findings should stay close to the participant's *voice*.

The *ownership* of the study's findings is shared between the researcher and the participant. During the study, the researcher serves as a guardian or *proprietor*, responsible for protecting the data. The story belongs to the participant and the products of the research, including the analysis and write up, are shared (Glesne, 2016).

Security of Data

The researcher also has the responsibility of securing the data and maintaining the participant's anonymity throughout the study and in the presentation of the study's findings. Even though a participant may ultimately choose to be named in the final presentation of his or her story, the participant's identity will not be revealed until the final consent and release of information has been completed. This enables the participant the chance to change his or her mind and maintain anonymity. Access to the data should be limited to the researcher, transcriptionist, auditor, peer debriefer, and peer examiner, and only while they are carrying out their duties (Glesne, 2016).

When not in use all data will be kept, stored, and locked securely. Recorded audio conversations and transcribed data will be stored on a personal electronic device, protected by a password to which only I will have access. When not in active use, the password-protected device and any other documents will be stored in a locked file cabinet in my home. All data, notes, audio recordings, and drafts will use a double-locked system. This applies to the peer debriefer (methodological consultant), peer examiner (who reviews the coding system in relation to the raw data), and transcriptionist (who generates the verbatim transcripts from the audio recordings) as well. When they are in possession of password-protected audio recordings, notes, transcripts, or drafts, they too will secure these documents in a locked file cabinet to which only they have access. Any documents sent over email will be password protected and will not contain the participant's name. The password will be sent in a separate email. The peer debriefer, peer examiner, and transcriptionist will not be permitted to save files on their computers or hard drives.

Purposive Sampling and Bounding of the Study

Qualitative research aims to build and enhance theories; thus it is most beneficial to use participants who have extensive direct experiential knowledge of the phenomenon rather than some who have intimate knowledge and those who have none as is the case in random, stratified samples. Since the intent of qualitative inquiries is to build and refine theory, to inductively construct more inclusive, robust theories that capture the breadth and depth of a phenomenological experience, the qualitative researcher selects information-rich cases in order to uncover aspects of the phenomenon of interest that go beyond what is already acknowledged in the extant literature. Depending on what the aim of the study

is, the researcher might want to look at “outliers” or people whose experiences represent gaps in the current research. In this way, the qualitative researcher attempts to build theories that examine the full breadth and depth of a phenomenon rather than what the average or common experience of the phenomenon might be (Patton, 2002).

This study will use *atypical case sampling* in which one individual will be interviewed about his or her experiences with an ICD. This type of sampling uses a participant whose experiences are unusual or rare to some extent, setting them apart from the main population (LeCompte & Preissle, 2003). This study will use an individual who is at least 18 years old and had an ICD implanted at age 60 years old or younger. Atypical sampling is appropriate since the average age of ICD implantation is about 66 years old (Kurtz et al., 2010).

Gatekeepers and Participant Recruitment

Due to the phenomenon of interest, it is difficult to obtain a younger participant with an ICD. My work in a medical office has exposed me to individuals with cardiac devices, but all of the patients are older. I will use snowball or chain sampling to locate a potential participant. *Snowballing* requires identifying gatekeepers or informants who can help the researcher identify potential participants who may then identify others who are members of a hidden population (Glesne, 2016; Patton, 2002). I will provide the gatekeeper with a letter and an invitation to participate in the study. The invitation will include a brief introduction to the study and my contact information. The informant can present these letters to potential participants.

Once the Chaminade University of Honolulu Hawai'i Institutional Review Board have certified this study, I will contact gatekeepers and provide them with this information regarding my study. I will discuss the purpose of the study and benefits of participating in the study. I will inform gatekeepers of the importance of maintaining the confidentiality of individuals they have referred to the study. As gatekeepers begin identifying potential participants for the study, I will request that they provide these individuals with the written invitation from me to participate in the study. The invitation will provide the potential participants with information regarding the study and my contact information. The gatekeepers can present these letters to potential participants without knowing who will ultimately be selected to

participate. This will help maintain participant confidentiality. If a participant is interested, he or she can contact me directly. I can provide the potential participant with more information regarding the study, address any concerns, and answer any questions. At this time, I can also assess to see if the individual is a good fit for the study.

Data Collection and Analysis

Pre-Entry

The pre-entry phase of a qualitative inquiry involves the period of preparation in which the researcher engages prior to entering the field. There might be certain cultural factors that the interviewer should make himself or herself aware of in order to increase his or her cultural sensitivity and understanding. The researcher in collaboration with the participant should also choose an appropriate location for the interviews. This will allow the interviewee to feel more comfortable and will likely increase his or her ability to build rapport. Gatekeepers or informants can help the researcher with the entry process (Glesne, 2016).

I have not had the opportunity to speak with others who have had cardiac experiences similar to mine. I am only familiar with my own story and experience. The participant for this study may be of the same gender and similar age. It will be important to be aware of the participant's schedule and potential obstacles that might occur in meeting with the participant. Despite my own experiences, I must still strive to familiarize myself as much as possible with the experiences of the participant.

Review of biases. During the pre-entry period, a qualitative researcher begins to identify potential theoretical/professional, methodological, and personal biases that may impact the study, and to strategically identify ways to minimize the negative impact these biases may have on the study's outcomes (Glesne, 2016). These biases will be monitored by the researcher, peer debriefer, and peer examiner throughout the study, and the initial action plans will be refined as the study proceeds. As other biases emerge during fieldwork, the researcher will add to this list and continue monitoring both the initial and emergent biases with the assistance of his or her methodological support team (Glesne, 2016).

Theoretical biases. Theoretical or professional biases are the biases associated with one's professional role. As a student in clinical psychology, I have to be aware not to treat the interview like a

therapy session. One's profession can influence the direction an interview takes. It is important to remain aware of professional bias when asking questions during interviews. Unchecked, this is an important role management consideration (Glesne, 2016). In psychology, theoretical orientation can have a strong influence on the course and focus of the interview. Theoretical orientation can also impact the interpretation of the data collected. My theoretical orientation is grounded in person-centered theory. This might influence me to be more drawn toward areas of incongruence within the participant's story. I tend to also be drawn toward exploring conditions of worth that developed in the respondent's family of origin.

In order to stay on track and focus on the participant's story, I can make note of these in my field journal. A list of potential grand tour questions will be used to stay closer to the participant's story while attempting to minimize bias. Asking more open-ended and descriptive questions will allow me to gather more information about the participant's experience.

The role of the therapist in person-centered therapy is also similar to that of the qualitative researcher. The researcher attempts to create a safe environment that allows the participant to reveal his or her story. This is done by providing empathetic understanding. I just have to remind myself during interviews, though, that the aim of meeting with the participant is to learn from the participant, not to conduct therapy or facilitate change. I can be empathic but my role is not to be a change agent. Meeting regularly with my peer debriefer to discuss any of these issues or concerns after the interview will help address my emergent theoretical biases.

Methodological biases. Methodological biases often stem from the type of research training the researcher has received. Most researchers have primarily been trained in the positivist paradigm that is based on different assumptions than the interpretivist paradigm. The positivist paradigm is used to test theory. The interpretivist paradigm that informs qualitative inquiries is used to generate or refine theory. The researcher has to keep in mind that the phenomena under study are complex and be aware of a tendency to reduce the phenomenon into simple relationships between constructs or dimensions of the phenomenon. The intent of a qualitative inquiry is to gather rich and thick information that captures the nuances of a phenomenon holistically (Glesne, 2016).

While conducting my project, I also have to be aware of methodological drift. I have never carried out this type of study. Having some grand tour questions prepared for the interview will help prevent me from asking questions that are more correlational and causal in nature. Another consideration is role management. There are certain assumptions I have about this phenomenon but I have to keep in mind that I am there to learn from the participant, to hear his or her experiences and story. I have to pocket my own agenda and allow myself to embrace and hear the participant's experiences. Following the interview, I will use my field journal to log my initial impressions and ideas. I will be able to reference my journal throughout the research process. I also will meet with my peer debriefer and peer examiner regularly to discuss any of these issues or concerns between interviews and throughout the data analysis process and write-up of the findings. They will help me challenge any biases that I might not be aware of and assist me in figuring out how to manage my biases.

Personal biases. Personal biases are formed from our own life experiences and how we view ourselves, others, and the world around us. The researcher has to remember that his or her experiences might be a lot different than the experiences of the participant (Glesne, 2016). I have lived through my own experience of cardiac arrest and living with an ICD, but I have little exposure to others' experiences of living with an ICD. I have to remember that what I interpret and think might be true or relevant may not be from the experiences and perspective of the participant. Asking open-ended questions will allow the participant to freely share his or her experiences and keep my personal biases in check. I can also use my peer debriefer and peer examiner to address emergent biases and their impact on data collection and analysis. I will further ask the participant if he or she feels like I missed a topic or issues due to my biases. These question can then be used in subsequent interviews. The participant can also contact me after the interview with any questions or concerns.

Entry

The process of entry refers to the process of building rapport with a participant. Entry is a continuous process throughout the data collection and analysis process. There are many emergent challenges to consider during the ongoing entry process in qualitative research like: immersion and role management, participant selection, and informed consent.

Immersion. *Immersion* refers to the process of staying in the field for a prolonged time or having more contacts with participants over time. While immersion supports a deepening rapport and increased access to the participants' knowledge of the phenomenon, over time, immersion also presents challenges. It contributes to a growing familiarity and role complexity between the researcher and participants.

Role management. *Role management* entails a clear statement regarding the researcher's intentions for the research. In the care of this study, I must help the participant maintain clarity of my role as a researcher rather than a therapist. As the relationship between the researcher and participant deepens over time, it can influence the research process. A relationship cultivated through communication between the researcher and participant will enhance validity and provide richer data. Qualitative research uses fewer participants which allows the researcher to devote more time with the participant fostering the relationship and gathering rich data making it even more critical to protect this valuable resource from attrition (Glesne, 2016).

Two-part informed consent. Informed consent is important before starting the interview process. A two-part consent will be used in this qualitative study. The initial consent provides the participants with general information regarding the study and an outline of what the study entails. It provides information on what the study will be asking them to do, the risks and benefits of participating in the study, and the participant's rights. The second, or final consent, gives the participant the opportunity to adjust, add, or retract the final write-up. The participant will also be given the opportunity to review and approve any exemplar quotes that will be used in the final write-up. The first consent protocol involves seeking the participant's agreement to participate in the study and the final one involves seeking the participant's authorization to release the information gathered which will be used in the final write-up. In this study, a two-part consent is used because participants can only properly make an informed decision about the information disclosed to the researcher after the participant has the opportunity to review what he or she has shared throughout the research process (Rossman & Rallis 2012).

The two-part informed consent allows the participants to review the information gathered from the interview and have a final informed consent to release this information and have a final say in what will be

used in the final write up (Glesne, 2016). This is particularly important since the participant may have disclosed information during the study that he or she does not want included in the study or does not exemplify his or her experience. The participant has the opportunity to make edits and review the narrative and the identified themes to ensure they are consistent with his or her experiences. The second consent allows the researcher to use the findings with the consent of the participant.

In case of emergencies. The participant will fill out an emergency contact form and provide contact information for an emergency contact. I will only contact the provided emergency contact in the case of an emergency. The nature of my relationship with the participant will remain confidential.

If the participant experiences any psychological distress during the interview or during the course of the study, I will recommend that the participant contact his or her regular mental health practitioner. In addition, a Community Resource list of mental health clinics on O'ahu and the Honolulu Crisis Hotline information will be provided to the participant during the initial informed consent protocol. In addition, national online resources will be provided. These resources will be presented to the participant during the initial informed consent and will be referred to again throughout the interviews as needed. In the case that the participant becomes overwhelmed during an interview, I will stop the interview and recording. I will notify the participant that I have stopped recording and will debrief with the participant. I will encourage the participant to contact a mental health provider if needed. I will also notify and consult my research supervisor if the participant is experiencing significant distress.

Constant Comparative Analysis

Constant comparative analysis will be used as the approach to data collection and analysis in this qualitative study. Qualitative inquiries use an iterative process of data collection and analysis. The process includes semi-structured interviews, data management, peer debriefing, transcription, auditing, coding, peer examination, generating a narrative, and member check. This allows the researcher to inform each round of data collection with what has been uncovered in previous rounds of data collection and analysis. Data gathered in the field is analyzed thematically. These emergent themes are then tested or member checked in each subsequent round for emic accuracy (Strauss & Corbin, 1998). This method of data collection allows the researcher the opportunity to more thoroughly test hypotheses regarding the

nature and essence of the phenomenon from the perspective of participants. This helps improve the overall validity (trustworthiness) and reliability (transferability) of the findings (LeCompte & Preissle, 1993; Shenton, 2004).

Constant comparative analysis increases the researcher's ability to modify his or her understanding of the phenomenon as he or she immerses into the field and gains greater access to the emic reality of the phenomenon. This enhances validity. This type of analysis also challenges the researcher to identify new aspects of the phenomenon and its meanings with each subsequent round of data collection and analysis which eventually saturates thematic understandings of the phenomenon and increases the study's reliability (Strauss & Corbin, 1998).

Security of data. Access to the data will be limited to the researcher, the participant as requested and, to a limited degree, to my peer debriefer and peer examiner. My CRP Chair, Dr. Joy Tanji, and CRP Committee Member, Dr. Michael Omizo, will serve as my peer debriefer and peer examiner, respectively. I will consult with Dr. Tanji to discuss any challenges I may encounter throughout my research process. I will also consult with her regarding refinement of my coding scheme. I will consult with Dr. Omizo regarding coding strategies and interpretation of the data. Drs. Tanji and Omizo will only have access to the materials generated in my study while performing their duties.

Data will be delivered via email in a password-protected attachment or a password-protected data storage device (USB). Any information sent via email will be password protected and a separate email will be set containing the password. Any hard copies generated while performing their duties will be stored using a double lock system (in a filing cabinet in a locked office). All hard copies of data will be returned to me. No information will be stored on the peer debriefer or peer examiner's hard-drive.

In the case that I do not carry out my own transcriptions, the transcriptionist will be required to complete an agreement form that outlines the protocols to be followed while transporting, using and storing the interview data. Transcriptions of the recordings will be password protected. The transcriptionist will be either given a protected data storage device (USB) or will be sent the audio recordings via password-protected email attachments. The password will be sent in a separate email to the transcriptionist for greater security. The transcriptionist will be instructed not to save any files on his or her

hard-drive. All transcriptions must be saved on the data storage device provided as a password-protected file, or as password-protected files, and sent via email with a separate email sent to the researcher containing the password. When referring to the participant, a pseudonym will be used.

The confidentiality of the participant will be protected throughout the course of the study. However, any reports of suicidal or homicidal intent that appear to be imminent or any reports of abuse of children, elders, or individuals with mental or physical disabilities will be reported to the proper civil or legal authorities. My research supervisor will also be notified. Confidentiality may also have to be broken if the materials from this study are subpoenaed by a court of law.

Semi-structured interviews. Semi-structured interviews are typically used in phenomenological studies (Rossman & Rallis, 2012). Initially, the researcher may ask grand tour questions that invite the participant to begin revealing what is meaningful to examine. Once the process begins, the researcher has the flexibility to generate follow-up questions that allow the researcher to explore the phenomenon of interest in greater breadth and depth, always being mindful of what the participant believes to be most relevant to understanding the phenomenon. Different types of questions may be asked during the interview inquiring about experiences, behavior, knowledge or background questions.

Three semi-structured interviews and one-member check will be conducted. Face-to-face interviews will be held in a private and safe location of the participant's choosing where we can have a private conversation without interruption. If the participant feels like he or she is not in a private or comfortable area, then we will reschedule the interview.

During online or phone interviews, I will ensure that I am alone or in a private locked room in my home while the interview is being conducted. I will also ask the participant to be in a private and quiet setting that will allow him or her to speak freely with me for about an hour to an hour-and-a-half with minimal interruptions. Prior to starting the interview, I will get oral confirmation that the participant is in an appropriate environment for the interview. I will remind the participant that we will be discussing private information. If the participant feels like he or she is not in a private or comfortable area, then we will reschedule the interview.

Data management. Data management involves the process of creating running codes. It can be difficult for the researcher to complete full transcription, auditing, and coding before re-entering the field. This macro-level coding can be used to help generate the next round of questions. Running code involves coding by document rather than by sentence or paragraph. The researcher listens to the recording and writes down key points or phrases that capture the emerging focus of the interview. This can help the researcher find areas they might have missed in the interview or areas that the researcher wants to further explore (Glesne, 2016).

Peer debriefing. The researcher meets with a peer debriefer following each interview to provide support and go over the researcher's initial impressions of how the interview went. During the peer debriefing process, the researcher starts to develop emergent themes and coding. They also discuss conceptualization and methodology. The researcher works with the debriefer collaboratively in order to help maintain methodological rigor and problem solve methodological challenges in the field.

During the debriefing the researcher can also start to form a narrative and refine coding. The researcher can meet with the peer debriefer following the interview and before the researcher re-enters the field for a second interview. The debriefer's role is to serve as a reflexive sounding board for the researcher, providing support, a context for brainstorming hypotheses about emergent themes, consulting about methodological challenges, challenging researcher biases, and monitoring the overall rigor of the researcher's data collection and analysis strategies (Glesne, 2016).

Dr. Joy Tanji, my committee chair and advisor, will also serve as my peer debriefer. I will meet with her on a regular basis to discuss any challenges I am experiencing either in or out of the field. We can collaborate to make any adjustments throughout my research process.

Transcription and auditing. The researcher transcribes the recording of the interview. It is beneficial to transcribe everything in the interview and redact later (Glesne, 2016; Hatch, 2002). The transcription process requires a lot of time and effort. It is typically done by playing back the recording and typing simultaneously. Auditing requires the researcher to check the transcript against the audio recording to ensure accuracy. This portion of the research process will be completed by me. In the case that another individual beside myself carries out transcription. I will notify the participant and my committee in

case the participant knows the transcriptionist I have chosen and has consented to the use of the identified third party transcriptionist. Currently, I plan to transcribe and audit the transcripts myself.

In the case that I do not carry out my own transcription, the transcriptionist I select will be required to complete an agreement form that outlines the protocols to be followed while transporting, using and storing the interview data. Transcriptions of the recordings will be password protected. The transcriptionist will be either give a password-protected data storage device (USB) or will be sent the audio recordings via password protected files via email. The password will be sent in a separate email to the transcriptionist to ensure that the data is safely stored. The transcriptionist will be instructed not to save any files on his or her hard drive. All transcriptions must be saved on the data storage device provided as a password-protected file, or as password-protected files and sent via email with a separate email sent containing the password. When referring to the participant, a pseudonym will be used.

Coding. The first level of coding or macroanalysis in transcendental phenomenological method is typically referred to as *open coding* or *phenomenological reduction*. The researcher deconstructs the data into smaller units of meaning. The researcher wants to capture the essence of each unit of data by assigning it a low inference code. With low inference coding, the researcher tries to remain close to the vernacular of the participants (Moustakas, 1994; Strauss & Corbin, 1998).

In the next level of coding, the researcher clusters smaller units and clusters of units into successively more inclusive categories and subcategories. This process of clustering themes into thematic categories and subcategories is referred to as *imaginative variation* (Moustakas, 1994; Strauss & Corbin, 1998). As the process proceeds, each meaning unit is compared against other meaning units to see whether they are different enough to be assigned a separate code and to see whether they are similar enough to be part of the same axial cluster (Moustakas, 1994).

Process coding is a type of imaginative variation in which the researcher identifies sequences in the data. Process coding can help the researcher examine the development or transformation of a phenomenon and its associated meanings or significance over time. The assumption is that social phenomena do not remain static (Strauss & Corbin, 1998).

The third level of coding is referred to as *synthesis* (Moustakas, 1994; Strauss & Corbin, 1998). As the study progresses, the researcher selectively codes pieces of new and emergent data instead of coding content that has already been identified in previous rounds (Strauss & Corbin, 1998). The researcher generates a provisional coding strategy for each interview, then creates an integrated coding list across all of the interviews (Weiss, 1995). If the researcher interviews more than one person, he or she will do this for each case and then determine whether or not to integrate the synthesized coding lists for each case into a single integrated coding list.

Peer examination. Following microanalysis of the data from each interview, the researcher meets with the peer examiner to review coding strategy and examine the fit between the codes and data. Similar to the peer debriefer, the peer examiner assists the researcher to elaborate, clarify, and explore (Glesne, 2016). Dr. Michael Omizo, my research committee member, will serve as my peer examiner. Following the participant interviews, I will consult with Dr. Omizo regarding the interpretation of the collected data and coding. Dr. Tanji will also be consulted regarding coding.

Generating a narrative. Generating a narrative is a creative process, but the researcher has to keep in mind that the intent of the narrative is to closely capture the participant's experiences (Glesne, 2016). The researcher has to keep in mind that her writing is a portrayal of someone else's experiences and approach the process with commitment and fidelity.

Member checking. After generating a narrative, the researcher conducts a member check with the participant. This allows the participant the opportunity to verify the transcripts and the written narrative. The participant can offer feedback to the researcher regarding the accuracy of how their story is being represented. In addition, the participant can make edits, add, or retract his contributions to the study (Glesne, 2016). The participant is also given the opportunity to review and approve the exemplar quotes from the interviews that are used to illustrate the themes in the narrative.

Methods of Verification

Validity

Validity in qualitative studies refers to the trustworthiness of the findings of the study. A study is valid, or has emic accuracy (internal validity), when the experience of the participants is aptly presented

from their perspective and not the researcher's perspective. Emic accuracy can be enhanced via methods that enhance managed subjectivity (Shenton, 2004). This process begins with entry or rapport building, immersion over time, relational ethics, and role management (Shenton, 2004). Epoché, which includes a review of biases, is also critical to enhancing validity (Glesne, 2016; Moustakas, 1994; Shenton, 2004). A field journal can be a good tool when conducting qualitative research (Shenton, 2004). This process can be further enhanced through the use of methodological consultation with a peer debriefer and peer examiner (Shenton, 2004). Ultimately, though, the most valuable way to enhance the trustworthiness or credibility of the findings is through member checking with participants; asking them whether one has gotten the story right (Glesne, 2016; Shenton, 2004).

While conducting my research I plan on documenting any emergent transference or biases that come up in the field journal. This journal can also be shared with the debriefer to inform bias checks during debriefing sessions. I will try to allow the participant to direct the majority of the interview process, too, showing me what is important for me to understand about his or her experiences. A good relationship with open communication between the participant and researcher will allow the researcher to collect richer data. This also will help ensure that I am not projecting my ideas about their experience. During each interview I will ask the participant for clarifications to make sure I am fully understanding their experience and perspective. In addition to these periodic member checks, I will conduct a final, more formal member check to verify emic accuracy.

Reliability

Reliability or analytical generalizability refers to the ability to apply the findings of the qualitative research study to the next study in terms of transferable thematic findings (LeCompte & Preissle, 2003). A study is reliable if it can be replicated with comparable findings (Shenton, 2004). By carefully documenting the process of the qualitative study, the study can be more easily replicated. Reliability can be assessed by using purposive sampling, and bounding and delimiting the study. Theoretical saturation is also an indication that the study's findings are likely to be transferable to other people engaged in similar phenomena.

Providing detailed documentation of the research process and design increases the reliability of the study. Another important aspect of reliability is providing reflection on the project and the effectiveness of the qualitative inquiry process (LeCompte & Preissle, 2003). For my study, I plan on being as specific in my approach as possible. I plan on doing this through thorough documentation. This will support comparability of my study to others conducted by other researchers. Over time, this will help with integration of findings across studies in support of generating provisional grounded theories.

Reliability can also be enhanced by seeking theoretical saturation. The more saturated or thick and rich the data, the more reliable the theoretical findings. This will include both shared and idiographic findings. Theoretical saturation is the point in which the data gathered becomes redundant and there is convergence of thematic clusters toward a core code (Glesne, 2016). Purposive sampling, entry, relational ethics, constant comparative analysis, peer examination, member checking can help achieve theoretical saturation. The member check is an essential method of verification in qualitative studies. This enhances both validity and reliability of the study. The researcher checks with the participant and can ensure an accurate presentation of the data.

Utility

Utility in qualitative research refers to the study's ability to have inform and transform understanding of and practices related to the phenomenon of interest. Utility is also related to the study's ability to enhance moral praxis. The study's findings are evaluated for fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity. *Fairness* refers to the inclusion of multiple perspectives and their complexity. This includes not only the multiple perspectives within group members but the multiple perspectives within one person. *Ontological authenticity* is when a study provides a new understanding of a phenomenon. *Educative authenticity* is when a study deepens understanding and adds breadth and depth to a phenomenon. A study has *catalytic authenticity* when the findings are presented in a way that readers can easily use and apply the data. *Tactical authenticity* is when a study can appeal and be beneficial to a wide audience (LeCompte & Preissle, 1993).

My hope is that this study has catalytic authenticity. The findings of the study might provide valuable information to training programs. The topic lends itself to tactical authenticity as well. I also want

to achieve ontological authenticity by providing readers a better understanding of the experience of an individual with an ICD. There is a wide audience that can gain benefit from gaining a better understanding of this experience including patients, physicians, psychologists, health care practitioners, family members of those with ICDs and interested readers. I want to provide educative authenticity by providing more depth to people's understanding.

Limitations of the Overall Design

This study will use the data collected and analyzed from interviews with one participant. This may result in a lower generalizability to the experiences of individuals with an ICD but can be replicated in the future adding to the validity of the findings. Other qualitative studies can also be informed by the findings of this study. Furthermore, the experience of an individual is complex and due to the time-limited nature of the study the experience of the participant cannot be fully explored.

CHAPTER III. EMERGENT FIELD METHOD

[Chapter III presents a discussion about the implementation of the methodology proposed in Chapter II. The intent of Chapter III is to provide the reader with methodological transparency concerning the challenges that may have been encountered in the field and how they were resolved.]

Pre-Entry

Review of Biases

During the pre-entry period, a qualitative researcher begins to identify potential theoretical/professional, methodological, and personal biases that may impact the study, and to strategically identify ways to minimize the negative impact these biases may have on the study's outcomes (Glesne, 2016). These biases were monitored by the researcher, peer debriefer, and peer examiner throughout the study.

I met with my committee chair following each interview. During this time, I shared my thoughts and feelings regarding the interview. Throughout each interview, I attempted to summarize what the participant was sharing with me in order to make sure I was understanding the participant's story accurately and not letting my biases influence my understanding. I also used my field journal throughout the research process.

Theoretical biases. Theoretical or professional biases are the biases associated with one's professional role. As a student in clinical psychology, I had to be aware not to treat the interview like a therapy session. One's profession can influence what direction in which one tries to take the interview. It is important to remain aware of professional bias when asking questions during interviews. This is an important role management consideration that the researcher has been cognizant of for a while (Glesne, 2016). In psychology, theoretical orientation can have a strong influence on the course and focus of the interview.

Theoretical orientation can also impact the interpretation of the data collected. My theoretical orientation is grounded in person-centered theory. My concern prior to entering the field was that this might influence me to be more drawn toward areas of incongruence within the participant's story.

In order to stay on track and focus on the participant's story I tried to make notes in my field journal. However, I found myself immersed in the interview and left with few notes at the end of each interview. Before each interview I wrote in my field journal any thoughts or feelings I had regarding the questions I would be asking or how I was feeling. At the end of each interview, I also took notes reflecting on the interaction and anything that came up for me or the participant. A list of potential grand tour questions was used to stay closer to the participant's story and to help minimize biases. Asking more open-ended and descriptive questions allowed me to gather more of the participant's experience. Following each interview, with the help of my committee chair, I generated follow-up questions or new questions for the next interview.

The role of the therapist in person-centered therapy is similar to that of the qualitative researcher. The researcher attempts to create a safe environment that allows the participant to reveal his or her story. This is done by providing empathetic understanding. During the interviews, I tried to remind myself that the aim of meeting with the participant was to learn from the participant, not to conduct therapy or facilitate change. That meant that I could be empathic but my role was not to be a change agent. Meeting regularly with my peer debriefer to discuss these types of issues or concerns helped address my emergent theoretical biases, especially those associated with my theoretical orientation and more familiar role as a therapist.

Methodological biases. Methodological biases often stem from the type of research training the researcher has received. Most researchers have primarily been trained in the positivist paradigm that is based on different assumptions than the interpretivist paradigm. The positivist paradigm is used to test theory. The interpretivist paradigm that informs qualitative inquiries is used to generate or refine theory. The researcher has to keep in mind that the phenomena under study are complex and be aware of a tendency to reduce the phenomenon into simple relationships between constructs or dimensions of the phenomenon. The intent of a qualitative inquiry is to gather rich and thick information that captures the nuances of a phenomenon holistically (Glesne, 2016).

While conducting my project, I had to monitor methodological drift. This was the first qualitative study I have done. Having some grand tour questions prepared for each interview helped prevent me

from asking questions that were more correlational and causal in nature. Another methodological consideration I monitored was role management. There are certain assumptions I have about this phenomenon but I had to keep in mind that I was there to learn from the participant, to hear his experiences and story. I had to pocket my own agenda and allow myself to embrace and hear the participant's experiences.

Following each interview, I used my field journal to log my initial impressions and ideas. I was able to reference my journal throughout the entire research process. I also met with my research committee regularly to discuss any of these issues or concerns between interviews and throughout the data analysis process and write-up of the findings. These meetings helped me challenge any biases that I was not aware of and assisted me in figuring out how to manage my biases on an ongoing basis.

Personal biases. Personal biases are formed from our own life experiences and how we view ourselves, others, and the world around us. The researcher has to remember that his or her experiences might be a lot different than the experiences of the participant (Glesne, 2016).

Prior to conducting this study, I had little exposure to others' experiences of living with an ICD. I only had my own experience of cardiac arrest and having an ICD. I had to remember that while my own experiences and interpretations might be true or relevant for me, they might not be from the experiences and perspective of the participant. Asking open-ended questions allowed the participant to freely share his or her experiences and keep my personal biases in check.

I used my field journal to document my thoughts and feelings about the questions I was asking the participant. This helped me to be more aware of my biases and promote more objectivity.

I also used my debriefing sessions to address emergent biases and their impact on data collection and analysis. I was sure to ask the participant if I had missed anything important after each interview. I also encouraged the participant to share with me anything that came up between interviews that they thought was important.

Entry

Purposive Sampling

Finding a participant that met the criteria for this study was challenging due in part to the rarity of a younger individual having an ICD. I am the only person I know that has an ICD. I reached out to gatekeepers, including medical providers and medical students via email and phone and informed them about the intent for my study. They were able to inform others in the health field about my study, including individuals who work with cardiologists, but many gatekeepers were unaware of individuals who met the criteria for the study.

I encountered individuals that were interested in participating in the study. One interested individual only had a pacemaker and not an ICD or pacemaker and ICD. After reaching out to gatekeepers, I was put in contact with another individual interested in the study. However, after speaking with the potential participant on the phone, I realized that the language barrier would be far too great to make the individual a good fit for this study. Another gatekeeper knew of a great potential participant, but the individual was just outside the age criteria.

Finally, I approached gatekeepers who were online group administrators, in hopes that my letter of invitation to potential participants might be posted. Many of the online groups had strict rules, though, that precluded posting of the invitation.

Even with the challenges of obtaining a participant, I was able to find an individual to participate that had an ICD placement who is below the average age of ICD placement. The participant in this study was a 28-year-old male of Filipino and Japanese descent who experienced sudden cardiac arrest and had an ICD placed when he was 22-years-old. At that time, he was a university senior and was playing college-level baseball.

Role Management

My role and the objectives of the study were clearly explained during the informed consent process. The participant was fully informed about what was expected and what the interviews would involve. He was also provided both consent forms and community resources prior to starting the first interview. The fact that the participant was the same age as me made it much easier for me not to fall into

a therapist role or expert role. Before and after each interview, we were able to connect over our shared experiences. It was a good way to strengthen rapport, make the participant more comfortable sharing his own experiences and debriefing.

Informed Consent Protocol

Prior to beginning our conversations about experiences living with and ICD, I discussed in detail about what participation in the study would entail. The participant was provided with a copy of the initial consent form before the first meeting. The participant was also provided with a community resource list with local community mental health centers and online support. I also had the participant complete the participant information form and an emergency contact form. During the initial informed consent, I explained the aim of the study, limits of confidentiality, potential risks and benefits, and participant rights. I also allowed time for the participant to ask questions and for any clarifications before starting the first interview. The participant was also reminded that he could stop the interview at any time if he needed a break and that he could choose not to answer any question that he did not feel comfortable with.

The two-part informed consent allowed the participants to review the information gathered during the interview and my draft of the final write-up before signing a final informed consent to release this information. This process allowed him the opportunity to make edits; to review the narrative, the identified themes, and the quotes I wanted to use to illustrate the themes.

At this time, the participant can also choose to remain anonymous or use their real name. The participant in this study decided to use his real name in this study.

Constant Comparative Analysis

Interview Process

The three interviews were scheduled either through email or instant messaging. The participant was working out of country and as a result we met over video chat. The time difference did not negatively impact the scheduling of interviews. The interviews were about one week apart. The interviews lasted about an hour-and-a-half. At the end of each interview, I allowed the participant to provide any concerns, comments or questions that might have come up during the interview.

Between the interviews, I would transcribed and audited interview audiotapes and prepare for the next interview. I also checked in with the participant to make sure he was not experiencing any emotional distress and to see if he was ready to schedule the next interview. I also met with Dr. Tanji between interviews to debrief my experiences of the last interview, discuss emergent themes and address any concerns I might have regarding the research process. These meetings provided me with greater insights and were very helpful in helping me identify themes.

Coding Process

I started the transcribing process the day after completing each interview. Usually within a day I was able to transcribe and audit the interview. I began the analysis process by generating running codes for each interview. While this process is not technically part of microanalysis, it gave me a chance to begin brainstorming the emerging themes of each interview. It gave me a general overview of each interview. I met with my committee chair to discuss these preliminary codes and themes and to discuss directions for the next interview.

As I completed verbatim transcripts and auditing for each interview, I began line-by-line coding. I would then cluster the codes into a nested outline. I identified quotes from the participant's interview that supported the identified themes. The coding process was at first overwhelming and challenging. With the help of my committee members, though, I was able to find themes that were not initially clear to me.

Member Checking

After completing the narrative findings, I met with my participant to review what I had discovered. Prior to our meeting, I emailed him a copy of the narrative findings. This occurred a couple weeks after the final interview was conducted. The participant was encouraged to edit the document as he saw fit in order to reflect his story more accurately. Together we read through the narrative and the participant commented and provided clarification in some sections.

During this meeting we also discussed how the overall interview and research process had been for him. Overall, the participant had a positive experience. He noted that he thought the process had been made easier because I also had an ICD. The research process had made him feel heard.

CHAPTER IV. Narrative Findings

Out of Left Field

James Robert “JR” Bunda remembered the Monday morning when he experienced his sudden cardiac arrest in 2012. He was a student athlete at the University of Portland in Oregon. He had almost completed the first semester of his senior year of college and had just turned 22-years-old.

I was probably in the best shape of my life. I was very determined to make that year a successful year to be drafted to be a professional baseball player.

His team had just finished their fall season and was preparing for their spring season. He was preparing for finals so took his class notes with him to the gym so he could study and workout at the same time.

After he finished working out, he headed to the track with two of his teammates to continue conditioning. Moments later he fell over and was face down on the ground. His teammates initially thought he was joking around. He does not remember what happened, but has been told the series of events that unfolded.

Then I wouldn't get up. Then one of my teammates was like something's wrong and turned me over and then my eyes were back and I had like purple lips and stuff. Then they freaked out. One ran to my coach's office. Then the other ran to get our weight coaches and trainers.

The people around JR acted quickly performing CPR and calling 911. The first responders attempted to resuscitate him four or five times before they were able to get a pulse. He was rushed to the hospital where he would spend the next week. After being in a medically induced coma for the first two days, JR finally regained consciousness.

I wasn't fully there. I remember getting a lot of messages on my phone. I couldn't—I didn't know how to work my phone because I was so out of it. It was crazy. I was like I don't know how to open my phone.

Even after being awake for a few days the gravity of what happened had not fully clicked. He described feeling like he was in a dream.

He also had many people visiting him in the hospital from his small college community, but he could not really remember who visited. Even though he had friends coming every other hour, he would forget that they had just been there. When people asked, he could not recall recent conversations that he had with them.

It was scary. I was trying to remember things because they were telling me to remember, like their dog's name.

JR remembers receiving support on social media while he was in the hospital. There was even a hashtag trending on Facebook in support of him.

Trying to Get Back to Who I Was

A Foreign Object

JR faced challenges of trying to get back to being normal following his cardiac arrest and the placement of his ICD. His ICD was implanted on day six of his seven-day hospital stay. The hospital stay was a blur. The decision for JR to get an ICD happened quickly. Most people around him, with the exception of his dad, thought the ICD was best for him. If one thing was clear, it was that he would need an ICD to continue to play baseball.

I just kinda vaguely remember them saying do you want to continue to pursue baseball and I said yes.

The decisions to get an ICD was not only a personal decision, but one that was influenced by the university.

One day it's just my body and the next day I'm having to think about something in my body. Two days after being discharged from the hospital, he was on a plane ride back home to Hawaii for the holidays. It was longest and most painful plane ride he ever experienced. He remembers thinking on the flight, "What is this foreign object in my body?"

Too fast. Reflecting back, JR thinks that his ICD was put in way too fast. It was implanted within a week of his sudden cardiac arrest. He would have liked to have at least a month prior to implantation. He had no time to process what he had just gone through or time to think about what the next steps were. Two life changing events happened within one week. He did not even have any options, like wearing a wearable defibrillator vest.

Emotions were so high that a lot of the decision was based off emotion. Everyone was scared. We almost lost him, so duh, put it in because if it happens again...it was based off of fear.

I feel like I was robbed of that decision. Not saying that it was the wrong decision.

He was not fully prepared for what it meant to get an ICD. He was not fully informed of the impact the implantation of an ICD would have on his mental health. He wishes that it was something that was more highlighted beforehand.

It made me think of so many dark thoughts that...I wasn't prepared for it.

Positive Figures

Coach. Following his cardiac arrest, JR was surrounded by people who were worried about him, saw him as a potential liability or thought he was fragile. He was not always treated like the strong athlete he still saw himself as, but as a person with a heart problem. Although he knows that people were acting with good intentions, it made him feel less normal. However, he did have some friends and a coach who treated him like the same person he was before the cardiac arrest and ICD.

He treated me like I was still JR. He was like "I don't care what happened to you, I'm gonna treat you the same." And that was probably one of the best things that could have happened to me at that time was just to be treated normally. And for it to come from a certain authoritative figure was very important to me.

Professor. Despite having difficulties getting approved to play baseball again, he remembered the university being accommodating in regard to his academics. JR had to make up the finals he missed during his hospitalization in addition to his course load for the final semester of his senior year. One of his professors had become the president of the university. JR met his professor in his office to take his final. Instead of having to sit down and take a written final, the two of them did the final verbally. The professor just wanted to see what JR had gotten out of the course. After the final was over, the two of them sat and talked about JR's experience with his recent cardiac event.

That kinda gave me a lot of encouragement that, hey I can do this. And it wasn't just about me getting the grades to finish my schooling, but it was more so to keep believing in myself and what I have in front of me.

JR was impressed by the amount of work he was able to accomplish, despite what he just went through. Even though he would not call himself an academic scholar, he was able to catch up and graduate on time. He impressed not only his parents, but himself.

Going through that experience also showed me a different side of me that I didn't know I had.

Physician. After college and finishing his club baseball season, JR went back to his home town. Coming home also meant that he had to find a new electrophysiologist. At this point he had been living with the ICD for a couple of years and was fed up with it. He was ready to move on.

I was done with it. I just couldn't wrap my head around it. I was trying so hard to live with it and be okay with it, but I wasn't and I wanted it out. I was determined to meet this new cardiologist and tell him to take it out.

JR knew that his doctor was a good fit. This physician was not afraid or cautious around JR. He was not scared of how he would react.

And he was like, "Look, when you look in the mirror look at yourself like a car. You have a dent in your car, but the car still works perfectly. You have no restriction on life. You can do whatever you want. This is just a dent in your car and it's just there to help you." That was the most real conversation I've had with a medical professional like...it was awesome.

He felt relieved by the doctor's response and impressed that he was able to take him off his high horse.

The doctor continued on and encouraged JR to pursue his dreams. JR expressed his concern about physical activity and how it might impact his defibrillator and leads. The doctor provided an example of a body builder with an ICD. This example encouraged JR to continue to pursue baseball.

ICD recipients. Shortly after the ICD was placed, JR sought a second opinion. He felt like his doctor was being too cautious with the restrictions he placed on him. The second electrophysiologist connected JR with another college student who experienced sudden cardiac arrest and was living with an ICD. Coincidentally, this recipient also played baseball and continued to play with an ICD. JR reached out and spoke with the recipient on the phone. This was the first person that he spoke with that was young and had an ICD. During the conversation, JR noticed how good the other recipient sounded. This conversation gave JR the confidence he needed to keep pursuing baseball. It inspired him to challenge his fears of playing baseball with an ICD. He was inspired.

Due to the rarity of a young person surviving cardiac arrest, there were few others JR came in contact with whom he could relate to with his story. However, he was able to connect with an older relative of his girlfriend who also had an ICD.

I felt like I was connecting and relating which is cool, you know, because I could relate with her, but at the same time I was like man, I have a harder time connecting like this with someone who is my age.

He has shared and talked with his friends about his experience of having an ICD. Although they have met him with empathy, their understanding of his experience was limited.

It's different when someone knows what you're going through because they've experienced it. It holds a different weight to how much it means.

Escape from Reality

Prior to his sudden cardiac arrest, baseball was a dream JR was chasing. He had been playing since childhood and made many sacrifices throughout his life for the sport. After having his ICD implanted the sport took on a new meaning.

Baseball then became my way of escaping reality of living with a defibrillator. My need to just wanna be back to normal from having a defibrillator and having something that made me look different, that made me feel different...to having something that made me feel like I wasn't whole enough to be on my own and live...it was filling a void. Playing baseball, for me, was filling the void of everything that living with a defibrillator comes with. It fulfilled my need of feeling normal because what was normal to me was being an athlete.

Baseball was a way for him to prove to people and himself that he was normal. That he was doing okay. It had always been a constant in his life and brought him the feeling of normalcy.

Nothing's changed, but clearly everything's changed.

Freedom Abroad

JR finally experienced freedom when he went to play baseball in Australia. It was the first time he was on his own with his "new self" and he did not have people trying to overprotect him. He was able to distance himself from the places and people that knew what had happened to him. During this time, he was given space to focus on his health on his own terms.

It was very healing to be away from everything, from everyone that I knew. So that was very healing, but I was still like very conflicted inside with having a defibrillator. I was having identity issues like—I felt very less of me.

Stress and Stress Relief

During times of more stress JR tends to have more stress about his ICD and has more negative feelings toward the device. As an athlete, he is even more aware of how he might impact his ICD.

I always have it in the back of my head: Am I gonna do something in my physical exertion that will make my heart beat go way too fast or something? Am I gonna get to a place where my heart is gonna stop again and this defibrillator is gonna act?

A flood of questions of what might happen fill his mind. These are new thoughts that he never had before having an ICD.

Everyone without an ICD won't ever know, but it's just something that I have to deal with. So in that sense, it's normal for me.

However, having a better understanding of what might happen and how the device works makes it easier for him to cope. He is able to walk himself through what to expect.

With his ICD, JR is more aware of his sleeping habits. Sleeping on his left side, the side of his defibrillator, causes some concern.

I freak out if I'm gonna like move it in a certain way, you know. So I'll wake up in the middle of the night sometimes and I'll like turn around because I'm kinda afraid.

When he has been stressed, he has had the same alarming dream a few times. In the dream, his ICD is hanging out from his chest.

Although getting an ICD is not something JR wanted, he realized that it provides some encouragement. What was at first frustrating for him, has become a challenge for him physically. He has had to figure out how to play baseball with the ICD.

Being able to be physical and, specifically for my life, do something that I love to do physically also reminds me each day that I can still do what I want to do in this life.

JR's experiences have changed his perspective on interpersonal problems. He looks at them with a different lens and tries not to sweat the small things.

When you go through a life or death situation you're really just grateful to be alive so you're just like...are we both alive? We're good...leave it at that.

However, his outlook sometimes gets interpreted by others that he does not care. Part of the reason is that he does not want to use his energy arguing about a small problem. The other part is that stress brought on by an argument can lead to stress about his heart.

Your heart starts racing sometimes, you get into a panic mode and then I start to get into the thought, "Okay, what is this going to do to the ICD? How is my heart going to be affected?" That's where I shut down. Being in a relationship is hard in that sense because when relationships do get hard then the anxieties come up and then I'm thinking about my heart and ICD. Not about the relationship.

Rest

Even though it has been years since his cardiac arrest and ICD placement, JR finds that he gets easily fatigued. He expects that at some point he will hit a point where his chest will start causing him discomfort. This happens whether he is on the field, working a desk job, or on vacation.

It has become routine to make sure that I get the rest that I need to be able to enjoy.

He has found that a routine and having high spirits helps, but when his schedule gets busy, it is harder to manage.

Life goes really fast sometimes. That's when it is harder to come by rest. That's when sometimes it can get really bad and hard to cope.

It took time for him to anticipate needing rest and to prioritize it, but now will take time off if he needs it.

How Other People Show Care

Teammates. At some point or another, people on JR's team find out that he has an ICD.

Sometimes it is because they notice him shy away from a playful slap that is targeted toward the left side of his body. Other times it is because they accidentally hit his ICD and ask him what they hit. After explaining, he has often had people treat him like he was more fragile.

In my mind, I'm like you're the last person that needs to tell me what I need to do or can't because I've lived with this for seven years now and you have no idea. So that...I have to really pick and choose the depth in which I go into sharing with people. I also have to pick and choose when I allow myself to hear someone else and let it affect me or kinda just brush it off and ignore it.

At first, he would get defensive after hearing his teammates' comments and reactions. He remembers some people's reactions being over the top. Now, he can laugh at some of these comments. He realizes that not everyone can empathize with his experience. For more approachable and open individuals, JR will choose to share his experience. But for those that seem to lack understanding, he chooses not to disclose his story and to dismiss their comments.

They would tend to be more cautious for him. Although he recognizes that his teammates might not realize what they are doing, he found it to be irritating.

I don't have time to think about that kind of fear or what I can or can't do because I know what it's like to let that consume my thoughts because it did for a while, in the beginning and it just brought me to a bad place.

Two extremes. Different people in JR's life tried to normalize his experience by just ignoring his cardiac arrest and ICD. In the beginning, that worked for JR because he did not know how to process

what he had been through. It made sense at that time to him. On the other hand, he had some family members that would constantly ask about his ICD which would irritate him. He said he wished there was more of a balance in how the people in his life approached bringing up his ICD.

Uncertainty

Blood clot. After getting back onto the baseball field in college, JR unexpectedly developed a blood clot. He was finally getting to a point of having more normalcy in his life, when he had an unexpected complication.

We went to the hospital and it turned out I had a blood clot and they were like yeah you need to go on immediate blood thinners right now. That was the start of like just...total...everything shifted inside of me. I really like...I was so down. The team doctor was like “your career is done for good now.”

Suicide ideation. Following his blood clot, JR was told that his baseball career was over. It was like all of his hard work had been for nothing. Things were crashing down and this lead him to feel depressed and suicidal.

I would go to sleep praying that I would not wake up. Then I would wake up thinking why am I still awake. There were a lot of days and nights like that. Pretty rough time. That period is when everything started to hit me. Everything.

The impact of living with an ICD started to sink in and so did feelings of guilt. He started questioning his life and felt guilty for what he put his family through with his cardiac arrest.

He remembers having so many days where he just wanted to rip the device out. He never wanted the ICD. In the first few years of living with an ICD, he said he would just “go crazy” and feel like he wanted to kill himself. He is thankful that he did not follow through with any of his suicidal thoughts. He feels like he was close to acting upon it and that it was a miracle he did not.

So many days I wanted to rip it out. I don’t know... then I would go crazy and want to kill myself. He does not want other individuals living with an ICD to feel how badly he did. He realizes how difficult it is to handle those emotions and how easily his life could have gone another way. By sharing his story, he hopes someone else can choose the better way too.

The device at work. JR has been shocked by his defibrillator a couple of times, but did not know that he was shocked due to its low voltage. It was an upper chamber issue. Even though he was not shocked in the first five years of having the ICD, he worried when or if his device would fire. He has also

had the device go off while he was sleeping to put his heart “back into rhythm.” It felt like a ticking time bomb.

It freaked him out to have something happen inside his body without knowing. He knew the device could go off, but was under the impression that it probably would not need to. It caused him to worry more about getting shocks in the future. To help ease his stress he tried to educate himself more on the ICD. He learned more about why the device might kick in and the different severity levels of shocks. His physician provided him some information and a family friend, a physician, also helped JR and his family to understand the device better.

Do I know how to live with an ICD? Although he has become more accustomed to living with an ICD, JR is still trying to figure out how to live with the device. He feels like he has only recently gotten a handle on how to adjust.

I don't even know if there's any way to say that I've mastered what it's like to live with an ICD. Yeah it's been seven years, but do I still know how to live with an ICD? I have no idea!

Having no template or guidance on how to deal with his sudden cardiac arrest and ICD left JR feeling really lost. This initially made it difficult for him to just keep moving forward. Thinking about the future is overwhelming. When considering getting into a serious relationship there are many unanswered questions that weigh on him.

Are they gonna come out with new types of ICDs? Smaller ICDs? More comfortable ICDs? When my battery dies, how do I...when I replace it...it just seems really complicated and I don't want to impose any burdens like that on someone.

It makes him think about how others see him. Sometimes he wonders if they see him as a sick child. So, instead he tries to focus on the present.

You want to get back to being normal, but you're definitely not normal. Things are different.

Plan B. JR has spent time living abroad and playing baseball at different levels. Every year he has to prepare, mentally and physically, for his next season. He informs his electrophysiologist of his travel plans and makes sure to follow up with him when he comes home. It is stressful to have to plan for his trips because it forces him to think about what could happen while he is living abroad. JR's travel plans require a lot more thought now that he has an ICD. Thinking about something happening with his heart or ICD while he is abroad makes him feel anxious.

Every year it's like I'm preparing to go do this. I have to make sure, cross my fingers, that everything's gonna go well. I've learned to adapt and I've learned to live with it. I know my threshold, my limit, of what I can do in a day.

He has kept playing not only because being an athlete has been part of his identity for as long as he can remember. It is part of what makes him feel normal. He has also kept playing because he wants to inspire and show other individuals living with a defibrillator of the possibilities open to them.

He or she may be 21 years old. I know a 10-year-old boy that got a defibrillator because he went into sudden cardiac arrest, you know. That keeps me going to keep playing so that he can see that he has a whole life ahead of himself and having a defibrillator can't stop him from doing anything. That's the same freedom you had before the defibrillator because when you get one in you wrestle with the thought of your limitations and what normal is and my normal has now changed.

The uncertainty of his baseball career, due to his ICD, led to JR searching for a career back-up plan. His own experiences led him to be interested in pursuing a path in the mental health. While continuing to play baseball, he has been pursuing a master's degree online. Seeking support from his pastors also inspired him to want to help others.

The journey of really discovering me and what I needed to heal emotionally, mentally, spiritually, physically...I guess pointed in the mental health counseling direction.

In the future, JR hopes to reach a young male athlete who has experienced cardiac arrest and is living with an ICD. On a broader scale, he is especially interested in working with any individual with who has experienced a sudden cardiac arrest or lives with an ICD. He also hopes to help families who have had a member go through a traumatic experience like cardiac arrest.

Whether it's a medical issue or you've dealt with something traumatic, it can pose a threat to your daily normal life that can also disrupt your normal flow and relationships.

Through his own experiences he believes he can really connect with and help individuals and families.

Sharing My Story

JR's cardiac arrest was not only news to his family and friends, but his entire college community. During college many already knew his story whether he shared it with them or not. It was helpful to let the story do some of the work for him. He appreciated the fact that someone could read or hear about his story and be inspired. However, their knowledge and understanding of his experience was limited to the surface.

Interviews. JR has shared his story through baseball. He said that each time he joined a new baseball team he would be interviewed.

Sharing my story is something that I've always done since I knew it was something that would help me heal and kinda keep me going. I always try to help others understand where I was so maybe that they kinda understood the reason why I would act a certain way that wasn't how I usually would act from before.

He realized during the interview process of this research project that no one would ask him how he was doing after talking about his traumatic experiences.

I would also kinda just deal with it, with the emotions that would come with sharing.

JR likes to share his story and thinks it is important. He does not expect the people he shares his story with to follow up with him, but he realizes that it is important for him to be able to debrief afterward on the experience of sharing his story. People might not realize that when he shares his story there is an internal process happening at the same time.

Church. Shortly following his cardiac arrest, JR's church asked if he could share his story.

Initially, he agreed, but when he started to put the story together he realized he was not ready.

I was going through the process of putting the pieces together. It was the first time that I was opening up to anyone and putting it on paper, talking to people. And they were telling me you should say this and this and this and I was like that doesn't make sense. Anyway, it got to the point where I realized I wasn't ready to share. That also kinda showed me....I realized that I was not okay.

Feeling overwhelmed, he broke down. Friends and family were offering him comfort and telling him it was okay, but he was not okay.

After some time had passed, JR found comfort and healing with his church community. He felt safe and comfortable to share his story from his perspective.

I needed just a safe community to be around. That's what I needed. I was able to like really just process through everything bit by bit, every little detail of what happened and I could do it on my terms.

He was met with a lot of compassion and empathy from those with whom he shared his story. As he shared his story, different emotions emerged and he was able to experience them as he shared his story.

I was just an emotional wreck and I felt like I could just be that emotional wreck.

He is thankful that his family encouraged him to seek support from the people in his church. It helped him to keep hope when he was dealing with issues of life and death.

Romance. Sharing his story was also a factor in forming new romantic relationships. JR wanted a romantic relationship, but was not ready in the first couple of years.

In the beginning I couldn't get to a place to even open up to be open to a relationship because I was guarding so much. So each time I tried I became more open.

In college people were somewhat familiar experiences that he had gone through, so he would not bring it up. He remembers wanting to date, but was not able to and he was not sure why.

I guess there's a parallel in that the more I learned about myself and the more I processed and healed and faced my reality, it would become easier to talk about it.

In his current relationship he was able to share his story with his partner and feel accepted. She was able to hear his story, but did not see him just as his device. Although he wants others to be identified with his ICD to inspire others, in more serious relationships he wants to be seen more normally.

Advice

Emotional Follow-Up

Following his cardiac arrest, JR was provided online resources for his sudden cardiac arrest, but he was not given any direction for where to go for support for his ICD. He had to do his own research. He was on his own. He was able to find a website that had a story of a construction worker who got an ICD. The construction worker had the ICD implanted because he needed to keep working in order to support his family. This story inspired JR to keep going, find his physical limits, and see what would happen.

Obviously there is a healing process physically that needs to happen, but there's also an emotional process. Physically, we go in to make sure every year we're good...to make sure the lead and the device are good, but there's no follow up on your mental or emotional well-being.

JR would have liked to have been provided with more resources, like a list of groups. When he was ready to, he could use the resources. He would be able to connect and hear other people's stories, whether online or in person.

JD recognized the impact the ICD placement had on his mental health. He would like there to be more emphasis on its impact, like informing family members to keep an eye out for the recipient's mental health.

Supportive and Patient

At different points in his ICD journey, JR says he has needed different things. For example, he wishes there would have been someone with similar experiences to turn to. One thing that has remained consistent and that has been the biggest help is his supportive family. He advises people who are close to individuals with an ICD to always be patient and supportive.

It is really not telling how that person should deal with it or how that person should cope with having an ICD, but letting that person express everything, every emotion they're having about having it. One day they may feel hopeful and grateful for having it, but another day they may just absolutely want to destroy it.

A Safe Place for Expression

JR emphasized the importance for others living with an ICD to provide a safe place for the expression of a variety of feelings. He acknowledges that although others without an ICD might not fully understand, they can provide an environment where frustrations can be heard.

Just make sure you have a safe place where you can fully express what you're dealing without having to feel that the other person needs to understand. There's not a lot of people who are young that have ICDs so not a lot of people are going to understand. If you do find someone that can relate to you then that's gold because there isn't a lot. If you don't have anyone at the time don't expect others to get it. Just make sure you know that you have somewhere safe to be able to express.

Summary

JR had his life thrown off track by his cardiac arrest and ICD placement. This small device has impacted multiple areas of his life including daily living, self-concept and meaning, career, and personal relationships. Despite having cardiac problems, he received a bachelor's degree, plays professional baseball, is pursuing a master's degree, has lived abroad, and continues to pursue his interests. The heart of JR's story is figuring out how to feel normal again. Figuring out what it means to live with an ICD has changed for him over time and continues to evolve. Despite the number of years that have passed since his cardiac arrest and implantation, his path to healing is ongoing.

The support and acceptance by his family helped him navigate through stormy waters. The support of his family, church community, physician, coach, and others allowed JR to feel accepted, encouraged, and hopeful. These individuals also provided him a safe space to share his emotional experiences living with his ICD.

Through his own challenges, he realized the impact that an ICD can have on mental health. He hopes that in the future the impact an ICD can have on an individual's mental health is more acknowledged. Online resources and connecting with others living with an ICD are ways that could help normalize the experiences of living with an ICD.

CHAPTER V. DISCUSSION

The intent of this study was to discover the experiences of a young individual with an ICD. There is limited literature on young individuals with an ICD. The main themes identified by the participant in this study were psychosocial adjustment and trying to gain a sense of normalcy.

The research questions for this study guided the interviews. Research questions helped pinpoint the overall idea of the study and helped to focus the area being explored. These questions also helped provide some boundaries for the study. The questions used to guide a qualitative inquiry were open-ended, non-directional, and they focus on perceptions, meanings and process (Glesne, 2016). In the following section the questions will be addressed in a broad manner.

The main questions asked in this study included:

- (1) What is the nature of having an ICD?
- (2) What is the experience of having an ICD?
- (3) How does the experience of having an ICD change over time?
- (4) What is the meaning of living with an ICD for a young adult?

Nothing's Changed, but Everything's Changed

There are a small number of young individuals who live with an ICD. Young individuals experience significant lifestyle changes that are different from older recipients. Although younger recipients report better general health, the quality of life and emotional functioning is better for older recipients. There are some shared experiences between older and younger ICD recipients, but there are some differences (Sears et al., 2001; Dunbar et al., 2012). JR experienced a range of adjustment issues since having his ICD implanted. These included feelings of depression, anxiety, suicidal ideation, and identity issues. Psychological distress is common among individuals who receive long-term ICD therapy (Shiga, Suzuki, & Nishimura, 2013).

Young adults are supposed to have their whole lives ahead of them. There are many dreams that have yet to come to fruition. Erikson's (1968, 1968, 1997) psychosocial developmental model identifies the following tasks for individuals in young adulthood (18-40 years): gaining independence, establishing intimate relationships, managing career decisions, and parenting. When an unexpected event occurs, like

a sudden cardiac arrest or ICD implantation, dreams and goals have to be reevaluated to incorporate the new normal.

Due to the uncertainty of his device, JR finds it difficult to think about the future. There are many variables to consider with his heart and ICD. Not abiding by a strict plan can make living with uncertainty easier (Flemme et al., 2011). Young individuals face different challenges than older ICD recipients. Older recipients often times are no longer working or have an established career, they are married, and have grown children. Younger recipients have the challenge of figuring out and establishing a career, finding a romantic partner, and starting a family or raising young children. Other concerns of young adult recipients might include passing their cardiac condition to their children and financial stability (McDonough, 2009; McKnew, 2013). Although individuals with ICDs face much uncertainty, many are not rendered powerless by it. JR has had to make adjustments to his daily life, but he continues to follow his goals. It was not easy, but he was still able to pursue his dream of playing baseball even with an ICD. He is also pursuing his master's degree due to the uncertainty of his baseball career.

Erikson laid out different psychosocial stages and identified the unique life challenges associated with each stage. At each stage, individuals restructure their identity in order to include new elements and experiences. Identity development has been shown to continue well into the late 20s (Carlsson, Wängqvist, & Frisé, 2015). An ICD implantation is an experience that needs to be incorporated into one's identity regardless of age. However, younger individuals live with the device for a longer period of time than older recipients (Dunbar et al, 2012; Sears, et al., 2001; Sherrid & Daubert, 2008). Because it is a long-term treatment, the meaning of living with an ICD is likely to have more impact and shift more over time as the individual progresses through multiple developmental stages.

JR experienced his cardiac arrest and had his ICD implanted when he was in his early 20s and a college student. He had already established a sense of independence by going to the mainland for college, but his ICD took away some of his independence. He had many limits set on him and many people hovering over him. His cardiac arrest and ICD implantation also came at a time when he was exploring career options, primarily playing professional baseball. There was an extended period of time where he thought that was no longer possible due to a blood clot, a complication due to his cardiac arrest.

This disruption caused him great distress and led to feelings of depression and suicidal ideation. Due to the continued unpredictability of living with an ICD and surviving a cardiac arrest, JR's identity will continue to evolve in order to incorporate new experiences.

JR's first electrophysiologist, the one who placed the ICD, was more conservative. He informed JR that the most physical activity he could engage in was a light swim or a bike ride around the park. For such an active person, this news was overwhelming. JR struggled to envision his life with just being able to go for a leisurely bike ride and not being able to play baseball. What was the point of living? This was a difficult situation for an otherwise healthy young male to grasp. He felt like he had not really started living his life yet and that his possibilities were reduced.

Living with an ICD is an adjustment that changes over time (McKnew, 2013; Ooi et al., 2016). Studies on individuals with an ICD have found that many participants experience feelings of anxiety, fear, depression, helplessness, anger, insecurity, and uncertainty shortly following implantation (McDonough, 2009; Williams et al., 2007). Fear and anxiety have been found to be the most prevalent (McDonough, 2009). ICD recipients who have experienced more shocks are more likely to develop psychological issues, including depressive and anxiety symptoms (Jacq et al., 2009). Despite not being aware of the shocks he has experienced, JR still experiences feelings of anxiety about having problems due to his ICD, including getting shocked.

Many individuals report having a more positive outlook on living with an ICD after having it for a period of time, but some experience intermittent periods of not feeling grateful (McKnew, 2013). JR cognitively knows why he needs the device. He knows that the device is there for his heart and to keep him alive. Despite constantly trying to look on the brighter side of things and thinking positively, there are some days when it is harder to do that. Other individuals also struggle with accepting the device, despite knowing the benefits of having the device (Dickerson, 2002). The participant often referred to the ICD as a foreign object in his body. Other individuals also relate to their ICD in the same way (Linder et al., 2013).

Living with an ICD comes with a lot of uncertainty. Recipients have to accept the ICD, the possibility of shocks, a change in body image, lifestyle adjustments, family and friend perceptions, and

fear of complications (Dunbar et al., 2012; Flemme, Hallberg, Johansson, & Stromberg, 2011; Jakub, 2018; McKnew 2013). The participant emphasized that his adjustment to living with an ICD has been an ongoing process. Living with uncertainty is a part of adjusting to living with an ICD and has to be accepted and incorporated into the new normal (McDonough, 2009). There is uncertainty with not only the device, shocking the individual, but with the disruptions the ICD and underlying condition have had on social roles and relationships and the future. Although quality of life has shown to improve over time for individuals after ICD implantation, a portion still feel like they do not have a normal life like everyone else (Verkerk, 2015). The participant discussed how his ICD impacted his relationships with friends, family, teammates, and romantic relationships.

Uncertainty and unpredictability can also contribute to a feeling of helplessness and a lack of control resulting in depressive symptoms. Anger and resentment is also a common reaction towards the device (Bolse, Hamilton, Flanagan, Carroll, & Fridlund, 2005; Garrino et al., 2018; McDonough, 2009). During the first few years following implantation, JR reported that he felt a lot of anger and frustration about certain events that came after his ICD implantation. Through his graduate school courses in counseling he has been able to gain insight into why he reacted with anger.

Social comparison theory can be used to help explain some of the adjustment issues that young adult ICD recipients face. This theory suggests that when there is no standard available for an individual to test their abilities, individuals then compare themselves to other people (Sears et al., 2001). Individuals with major medical problems may not be provided with the information they can use to understand their illness which makes self-evaluation more difficult. Lowered self-esteem may result from the individual seeing themselves as a victim or from others viewing them as a victim. JD reported instances of others, including his family, friends, and teammates, treating him as though he were fragile following his sudden cardiac arrest and ICD placement. Ineffective coping skills might also contribute to feelings of hopelessness (Affleck, Tennen, Pfeiffer, & Fifield, 1987). JR continues to discover what he needs mentally and physically in order to cope with living with an ICD and the stress that comes with it.

According to social comparison theory, individuals also compare themselves to groups or individuals to whom they feel similar (Sears et al., 2001). Due to the small number of individuals living

with an ICD, or who have experienced cardiac arrest, young ICD recipients have few people with whom to compare their experiences. This could lead to lower levels of self-esteem and more difficulty adjusting to living with an ICD. JR has encountered few individuals his age living with an ICD. He did not have anyone among his peers who he could talk to and could fully understand and empathize with his experiences. This likely contributed to his feelings of depression the couple years following his implantation. Support groups and having means to connect with people of the same age living with an ICD could have provided normalization and support (Dickerson, Posluszny, & Kennedy, 2000).

In addition to age, gender may also have an impact on psychosocial issues the participant faced. Around 60-70% of ICD recipients are men (Jakub, 2018). Research has indicated that women experience more difficulties adjusting to an ICD and have higher anxiety levels (Ooi, He, Dong, & Wang, 2016). Issues that women are most concerned about include scarring, clothing fitting over the device, sexual activity, and socialization issues (Sowell et al., 2006).

Like JR, other individuals have discussed the challenges of navigating their experiences with cardiac arrest as experienced by family or friends (Jakub, 2018). The cause of the cardiac arrest for participants in other studies was important to their subsequent adjustment. When the cause was unknown and they did not have any symptoms prior, it was more difficult to accepting the fact that they had experienced a cardiac arrest. Age was also an important factor in adjustment. Young men without prior symptoms had more difficulty adjusting than older men who had symptoms related to heart disease or failure. The decision to have an ICD implanted is sometimes made by physicians or family members and the recipient has minimal or no input into the decision (Jakub, 2018). Many ICD recipients wish there was more discussion prior to implantation (Linder et al., 2013).

Although JR had some say in the decision to get the ICD, in order to play baseball, he was not fully cognizant of what the decision meant for his physical and mental health. Consistent with the participant, many individuals report waking up from a cardiac arrest feeling uncertain (Bremer, Dahlber, & Sandman, 2009). Members of his family and his physician was in support of the ICD implantation. He wishes he had more time to process and make his decision.

Despite the ICD being mostly hidden, men have also indicated the importance of maintaining masculinity. Individuals tend to not like unwanted attention. Moreover, individuals are upset to be told to limit activities for others' fear of a shock. Men might then try to prove to others that they are not held back by their ICD (Jakub, 2018). JR did not appreciate others telling him his limits when they had no insight into the journey he had been through, physically and mentally, to be able to play. It is also possible that people, who tried to remind JR of his limits, caused him to push himself further physically. These reminders also may have helped him gain a sense of normalcy by ignoring the potential limits posed by having an ICD. In general, though, JR's drive was to regain normalcy rather than maintain a sense of his masculinity.

JR has always participated in sports and has been an active person. Prior to getting an ICD, he would play tackle football at the beach. He can no longer play the contact sports he once did because of his ICD. A part of him longs to be able to engage in activities he could prior to the ICD. He would have dreams of playing football again but wakes up knowing that he cannot.

In the face of challenges thrust upon JR since his cardiac arrest and ICD implantation, he has experienced positive personal growth. Posttraumatic growth has been indicated to have both emotional and physical benefits to individuals with chronic illness (Zeligaman et al., 2018). He found new ways to relate to others. While being treated for his blood clot, he found himself surrounded by people three times his age. He saw this as an opportunity to connect with others with similarities, despite the age difference. When considering whether to play baseball professionally after his cardiac arrest, he began to see it as an opportunity to inspire and inform others. Although JR experienced some anxieties living with his ICD and experienced a period of depression, he has gained great strength. Through his own negative experiences, he has discovered that he wants to help others through difficult periods of their lives.

Clinical Implications of the Study

This study reinforced the need for further research on the mental health of individuals living with an ICD, particularly young adults. It has provided insight into some of the unique challenges young individuals with an ICD face. These challenges should be more integrated into the treatment of ICD recipients. Individuals with an ICD report symptoms related to depression, anxiety, and posttraumatic

stress (Ingles et al., 2013; Sears et al., 2004; Webster et al., 2014). This information should be emphasized to the recipient and their family by health care providers. Appropriate community resources should be provided to the individual and family to use as needed. This might include the crisis line, mental health care providers that have experience working with clients living with an ICD, online resources and support groups, and local support groups. It also might be beneficial for electrophysiologists and other treating physicians to regularly screen for psychological symptoms and make referrals to psychologists when appropriate. Living with an ICD can have a significant impact on a recipient's mental health and challenges might not arise immediately after implantation.

Good rapport and communication is important between the treating provider and ICD recipients and their family. Open communication lines and the provision of ample information on what it means to live with an ICD can help recipients feel more in control of their situation. ICD recipients have reported an unsatisfactory level of input and discussion regarding ICD implantation (Jakub, 2018; Linder et al., 2013). Psychoeducation and ICD education is an effective tool for ICD recipients (Sears et al., 2004). Information can provide them with a better understanding of what the recipient is experiencing mentally and physically.

In-person and online support groups have shown to be beneficial (Dickerson, 2002; Dickerson, Posluszny, & Kennedy, 2000; McDonough, 2009). Connecting with same-age peers provides normalization and support. There is limited research on young individuals with an ICD, indicating that this population is in the minority. This might leave this population more vulnerable to isolation and the development of psychological issues. Although general ICD support groups may be beneficial, age-specific groups could generate a greater sense of connectedness (Williams et al., 2007). Currently, there are no in-person support groups for individuals living with an ICD in Hawai'i. Many online forums are geared toward or have more participation by individuals living with a pacemaker.

Although most young ICD recipients are able to return to work or school and physical activity, there are many psychosocial adjustments young individuals face. Peer support and health care provider support are important ways that can help make these adjustments easier and should be made easily accessible.

Limitations of the Study

This study used data collected and analyzed from interviews with one participant. The results of this study might have lower generalizability to the experiences of individuals with an ICD. Therefore, it would be important to replicate this study in the future to add to the validity and transferability of the findings of this study.

Furthermore, the experience of an individual is complex, and due to the time-limited nature of the study, the experience of the participant could not be fully explored. It is impossible to fully encapsulate a person's experiences in three meetings. Although a lot of data was gathered, the limited time frame may have prevented full immersion. It should also be noted that obtaining a willing participant for this study was difficult due to the personal and sensitive nature of the study.

Another possible limitation is that I have my own experiences living with an ICD. Although I think that this allowed me to more deeply understand the participant and his experiences, it is possible I was limited by what was more salient to me. The participant and I have a lot of shared experiences, but there are also many differences between our experiences.

Recommendations for Future Studies

It would be beneficial to replicate this study in the future to add to the validity and transferability of the findings. Future qualitative studies done with young individuals with ICDs would be beneficial in order to further understand the experience of young individuals, to continue exploring the commonalities and variability in experiences of these individuals.

A focus on individuals with an ICD in college is another area of further exploration. College students face a lot of transitions and typically live away from home. Exploring these dynamics in relation to living with an ICD is another area that should be explored.

Another area of further research would be to explore the experience of the treating electrophysiologists. Although physicians possess the clinical knowledge to treat individuals with cardiac problems that need an ICD, it would be informative to explore their understanding of what it is like for their patient to have an ICD.

Finally, although there is some research on the psychosocial issues individuals living with an ICD face, there is still much to be explored. In particular, it would be important to suicidal ideation and existential concerns among these individuals.

Conclusion

Although an ICD provides an effective medical intervention for life threatening cardiac issues, it alters other areas of the patient's life. It is critical for the health providers treating these individuals to understand the challenges they face long after implantation. This study adds to the limited existing research on young individuals living with an ICD. The participant in this study continues to face challenges of living with an ICD despite having the device for seven years. The findings of this qualitative study can inform future studies that explore the experience of a young individual living an ICD and further highlights some of the psychosocial issues that these individuals face.

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Appendix A

Argosy University, Hawai'i IRB Certification Letter



February 22, 2019

Shantha McKinlay
98-845 Kaahele St.
Aiea, HI 96701

shantha.mckinlay@gmail.com

Dear Ms. McKinlay,

Your Level 3 application, "The Experience of Living with an ICD," is fully certified by the Institutional Review Board as of 2-22-2019.

You need to abide by the requirements in any letters of permission you have obtained.

Please note that research must be conducted according to this application that was certified by the IRB. Your proposal should have been revised to be consistent with your application. Please note that you also need to abide by any requirements specified in your letter of permission. Any changes you make to your study need to be reported to and certified by the IRB.

Any adverse events or reactions need to be reported to the IRB immediately.

Your full application is certified for one year from 2-22-2019. Please be aware that if your study is not likely to be completed one year from 2-22-2019, you will need to file a **Continuing Review for IRB or Continuing Certification of Compliance** form with the IRB at least two months before that date to obtain recertification. If your proposal is not recertified within the year specified (365 days), your IRB certification expires and you must immediately cease data collection.

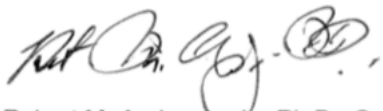
When you have completed your research you will also need to inform the IRB of this in writing and complete the required forms. You may use the **Project Completion Report** form for this purpose. Records must be retained for at least three years.

Good Luck with your research!

Please be careful not to lose this letter.

If you have questions, please feel free to contact me.

Sincerely,

A handwritten signature in black ink, appearing to read "Robert M. Anderson Jr.", with a stylized flourish at the end.

Robert M. Anderson Jr., Ph.D., Co-Chair
Institutional Review Board

cc: Dr. Joy Tanji

Appendix B

Chaminade University of Honolulu IRB Certification Letter



Institutional Review Board.
Chair: Claire Wright, Ph.D.
Vice Chair: Darren Iwamoto, Ph.D.
irb@chaminade.edu

June 22, 2019

Ms. Shantha McKinlay
98-845 Kaahale Street
Aiea, Hawaii 96701

Dear Ms. McKinlay:

This letter is to confirm receipt of your Argosy University Institutional Review Board (IRB) approval for "The Experience of Living with an ICD".

The CUH IRB IRB00007927 reviewed the above IRB external approval.

The Chaminade University IRB will accept your current number and will not require reapproval at this time. Your Chaminade IRB protocol number is CUH 089-2019. You will now be entered into our annual report cycle (due date below). Please use the attached Form VI to complete your annual reporting.

The final date for your Argosy approval is February 22nd 2019. Continuation of research after this date will require:

1. Submission of Form IV Final Report; and
2. Request for an extension letter to be submitted to irb@chaminade.edu 30-days prior to the expiration date of your Argosy approval. The Board may require a new protocol submission, so please do this as early as possible.

Effective proposal approval date: February 22nd 2019

Date of annual or final report due to Chaminade IRB: February 22nd 2020

Please submit a copy of your current CITI training certifiable by email to irb@chaminade.edu. Please be advised that if you submit future protocols to our IRB we will require updated CITI certification aligned with Chaminade's requirements.

Please feel free to contact the IRB above with any questions or concerns.

Kind Regards,

Claire Wright, PhD
Chair, Chaminade IRB Committee

Appendix C

Life with an Implanted Cardioverter Defibrillator (ICD)

Hawai'i School of Professional Psychology at Chaminade University of Honolulu

Script for Working with Gatekeepers

The following script is intended to be used to contact gatekeepers:

"Hello, my name is Shantha McKinlay. I am currently student at the Hawai'i School of Professional Psychology at Chaminade University of Honolulu. I am in the process of conducting a Clinical Research Project in order to fulfill my requirements for the degree of Doctor of Psychology in Clinical Psychology. In my study I would like to explore the experience of an individual living with an ICD. This topic has personal meaning for me. I also have an ICD and have my own personal experiences living with it. Through this study I hope to gain new insight and understanding of another young individual's experiences. I hope that you might be able to assist me in finding a participant for my qualitative research study. I am looking for an individual between 18 and 45 years old with an ICD placement or an individual that had an ICD implanted at age 45 years or younger and is currently 18 years or older. Would you be able to help me?"

(Wait for gatekeeper's response.)

"Thank you for your help! Before contacting any potential participants, I want to note that due to the personal nature of this study, it is important to keep potential participants' identities confidential in relation to this study. In assisting me, you would be helping me find people that are interested in participating in the study. I would ask you to give these interested individuals a letter inviting them to participate. This letter will provide them with a general overview of my study and my contact information. In order to maintain confidentiality, I ask that you not ask the potential participants if they have decided to participate in my study. Will you be able to keep potential participants' identity confidential?"

(Wait for gatekeeper's response.)

"Thank you! I appreciate your help in my study. Please feel free to contact me at 808-782-2550 or shantha.mckinlay@gmail.com if you have any further questions. Please contact me by phone if you have a potential participant and I will provide you with a letter to invite the individual to the study."

Appendix D

Life with an Implanted Cardioverter Defibrillator (ICD)

Hawai'i School of Professional Psychology at Chaminade University of Honolulu

Invitation to Participate in the Study

Aloha, my name is Shantha McKinlay. I am a Clinical Psychology doctoral student at the Hawai'i School of Professional Psychology at Chaminade University. I am in the process of conducting a Clinical Research Project in order to fulfill my requirements for the degree of Doctor of Psychology.

This topic has personal meaning for me. I also have an ICD and have my own personal experiences living with it. Through this study I hope to gain new insights and understanding of this experience from another young individual. There is limited research on the mental health concerns of young adults with ICDs and their experiences. This study will be beneficial to those with an ICD placement and family members, providing them with more insight into the challenges and stressors the individual with the ICD experiences. This study and future studies may prove beneficial for health care providers, helping them to incorporate proactive ways of addressing the mental health concerns of those living with an ICD.

I would like to invite you to participate in three interviews that explore your experience of living with an ICD. I would like to personally extend my invitation to you because I believe you possess unique insight into being a young individual living with an ICD. Your personal experience can provide valuable information to others with an ICD, family and friends of individuals with ICDs, and health care providers.

If you are interested in participating in this study or would like to know more about my study before making a decision about participating, please contact me at 808-782-2550.

Sincerely,

Shantha McKinlay

Appendix E

Life with an Implanted Cardioverter Defibrillator (ICD)

Hawai'i School of Professional Psychology at Chaminade University of Honolulu

Participant Information Form

Participant's Name: _____

Address: _____

Phone Number: _____

Email Address: _____

Please indicate your preferred method(s) of contact with the researcher, Shantha McKinlay:

☐ Phone call☐ Email☐ Text message

Appendix F

Life with an Implanted Cardioverter Defibrillator (ICD)

Hawai'i School of Professional Psychology at Chaminade University of Honolulu

INITIAL CONSENT FOR PARTICIPANT IN RESEARCH

1. *Who is the researcher?* Hi, my name is Shantha McKinlay and I am a student at the Hawai'i School of Professional Psychology at Chaminade University. I am conducting this study in partial fulfillment for my requirements for the Degree of Doctor of Psychology in Clinical Psychology.
2. *What is the aim of the study?* The aim of this qualitative methodological study is to explore the experience of a young individual's experiences of living with an ICD. The overall objective of this study is to help me understand more about your experiences and what they have meant to you.
3. *How was I chosen?* I will be interviewing one individual about his or her experiences living with an ICD. I have chosen you because I think you have valuable insights to offer. As a young individual with this experience you have a unique perspective and experience than most people living with an ICD.
4. *What will be involved in participating?* I would like to schedule four meetings with you. The first three meetings will last between an hour to an hour-and-a-half during which I will explore your experiences related to living with an ICD. Some of our interviews may take place via FaceTime, Skype, or other free online video chat software. Since the interviews may be conducted not only face-to-face but also via Skype, FaceTime, or phone, confidentiality and privacy may be compromised. Online and phone interviews may not be as secure as face-to-face interviews.

With your permission, I would like to audio tape our conversations and make transcriptions from the tapes, so that I may attempt to represent your perspectives with greater accuracy. I will obtain oral consent to record each recorded conversation at the beginning of each conversation. I would also like permission to take notes during the interview to better increase my accuracy in documentation and understanding your story and to remind me of areas we discussed.

I will ask you at the beginning of each session if you are ready to begin recording and I will verbally inform you when I start recording. If during our discussions you would like to take a break or say something off the record, I will stop the recording. I will let you know when I have turned the recorder off. While the recorder is off, anything you say will not be included in the study unless you repeat it later while the recorder is on. You also have the ability to pass on questions at any time or return to the question at a later time. You can also withdraw from the study at any time without having to state a reason and without any negative consequences.

Then I would also like to schedule a fourth meeting to share with you what I think I have understood from our previous meetings. I will provide you the opportunity to check the accuracy of my write-up representing your narrative. You will be able to make any edits or changes in how your experience is represented. I will analyze the themes that emerge from our conversations and create an integrated narrative. During this fourth meeting I would like you to make changes to the final integrated narrative as well. I will work closely with you to clarify or correct any areas that I may have misinterpreted. I would also like to take time to discuss your experience of the interview process.

5. *Who will know what I say?* In addition to me, members of my support team will have limited access to your audio tapes and transcripts in order to assist me. My support team includes my research adviser and research committee member who will serve as my methodological consultants: my peer debriefer, Joy M. Tanji, Ph.D., and my peer examiner, Michael Omizo, Ph.D., respectively.

Dr. Tanji, my adviser, will oversee this process and provide me with further instructional support. As my debriefer Dr. Tanji will help me to tell your story with as much accuracy and richness as possible. The role of my peer examiner, Dr. Omizo, is to check my analysis of our conversations. In the event that I am unable to transcribe our interviews, I will utilize a transcriptionist. I will inform you the identity of the transcriptionist to ensure your confidentiality. I will audit the transcripts to ensure accuracy against the audiotapes. My support team will have limited access to the information collected when carrying out their described roles. They will be informed of the requirement of maintaining confidentiality.

All data, notes, audio recordings and drafts will use a double-locked system. When the peer debriefer, peer examiner, and transcriptionist are in possession of transcripts Any documents sent over email will not contain your name and the documents will be password protected. The password will be sent through a separate email. The peer debriefer, peer examiner, and transcriptionist will not be permitted to save files on their computer or hard drives.

6. *What are potential risks associated with participation and how will they be addressed?* During the study, I will attempt to protect not only your confidentiality but anonymity as well. Since this is a small community, though, there is always the possible risk that despite my efforts, someone who reads the study may be able to figure out who you are. To minimize this risk, your name will not appear on any of the transcripts or in my provisional write-up. In addition, when not in use, all data will be kept, stored and locked securely. Recorded audio conversations and transcribed data will be stored on a personal electronic device, protected by a password that only I will have access to. When not in active use, the password-protected device and any other documents will be stored in a locked file cabinet in my home. The peer debriefer, peer examiner and research consultants will only have access to these materials when performing their duties as described above. In my journal entries and discussions with them, I will not refer to you by name. Instead, I will use a code name of your choosing.

Please indicate the name you would like me to use for you in my study:

_____.

Any reports of suicidal or homicidal intent that appear to be imminent or any reports of abuse of children, elders, or individuals with mental or physical disabilities will be reported to the proper civil or legal authorities. My research supervisor, Dr. Tanji, will also be notified. Confidentiality may also be broken if the materials from this study are subpoenaed by a court of law. My intent would be to ensure your safety and the safety of other by networking you to resources that could support you through current challenges. In such an instance, we might also decide to temporarily stop the interviews until you have the chance to access these resources. Some participants decide at the end of the study to be identified and we will revisit the release of information during the final informed consent at the conclusion of the study.

Although I do not foresee any major risks to you, talking about your experiences may bring up some unexpected memories and insights that can be upsetting. The remembrance and experience of intense feelings associated with critical experiences may be painful and unresolved.

Should this happen, I would like to stop the interview, turn off the recorder, and take time off the record to better understand what is coming up for you. Then, I would like to support you in deciding what may be the most helpful way to address these concerns.

This might include encouraging you to contact a mental health provider or withdrawing from the study. I will provide you with a Community Resource List as part of supporting you in caring for your overall well-being. Your welfare, above all else, is important to me. Whatever we discuss off the record will not be included as part of the data in the study. I will allow you to determine when we will turn the recorder back on.

7. *What are the potential benefits of participating?* Sometimes people find participating in a focused conversation to be beneficial insofar as it gives them a chance to talk about things that matter to them. You will likely benefit from the opportunity to reflect and share your personal experiences. It will also allow you to assist the researcher gain experience in qualitative interviewing. This study might also benefit other disciplines to better understand the individuals they treat. Participation in this study does not include any compensation.
8. *What are my rights as a participant?* You may ask questions regarding the study during any time, and I will attempt to answer them fully. You may withdraw from the study at any time without having to provide a reason and without fear of negative consequences from me. Your participation is voluntary. If at any time, you would like to speak off the record, you may turn the tape recorder off, then turn the tape recorder back on when you are ready.

Anything you discuss during this time will not be entered into the data unless you discuss them at a later date while the audio recorder. You may waive any question you do not wish to answer. You may also defer and answer the question at a later time.

You have the right to review my work at any point in the process. After I have generated a narrative of what you have shared with me during the study, I will give you an opportunity to add, revise, and remove material you believe does not accurately represent your experiences.

On August 26, 2022, when I have completed the requirements for my Clinical Research Project I would like to return the tapes of our conversations to you. Please indicate which of the following you would like me to do at this time (please check all that apply)

- ☐ Please return my audio recordings to me.
- ☐ Please provide me with transcript(s).
- ☐ Please destroy my audio recordings.
- ☐ Please provide me with a copy of the narrative write-up of my story.
- ☐ Please provide me with a copy of the entire clinical research project.

I am required by the Hawai'i School of Professional Psychology at Chaminade University of Honolulu's Institutional Review Board to keep the audiotapes and transcriptions of the study for three years following the completion of the study. This is so that I will be able to respond to questions by other researchers if needed. On August 26, 2022, I will shred the paper documents that I have from the study and erase the audio recordings of our conversations. Paper documents will include transcripts and field notes.

9. *What will be published?* As mentioned above, I would like to review the narrative write-up of my findings with you during our last meeting. At that time, I will ask you for permission to use certain quotes from our conversations to illustrate your experiences more clearly to others. You have the right to review these materials and decide which quotes you will allow me to include in my final write-up. You may also reword, add to, or decline my use of others.

Since this is a Clinical Research Project, it will be published and made available electronically by the Chaminade University Library. There also might be future opportunities to present this study at a professional conference. In this case, I will contact you to gain permission.

10. *If you want more information, whom can I contact about this study?* If at any point in the study you have questions about my study, you may contact me at 808-782-2550 or shantha.mckinlay@gmail.com. If at any time during the process, you have concerns about my study or interactions with you, or require clarification of your rights as a participant, you may contact my research advisor, Joy M. Tanji, Ph.D. at her direct line at 808-791-5206. If you have any questions regarding your rights you may also contact Robert Anderson, Ph.D., Chair of the Institutional Review Board of Chaminade University by phone at 808-791-5207.

By written notification to Shantha McKinlay, below, I _____ (printed name) indicate that I am an adult (18 years or older), that the information presented in this document has been reviewed and explained to me to my satisfaction, but that this procedure does not preclude me from seeking further clarification in the future. I understand the nature and intent of this study. I also understand my rights and what is being asked of me as a participant. I understand all of the above and provisionally agree to the conditions specified. I understand that I will be given further opportunity to complete this informed consent procedure at the completion of my participation— after I have had a chance to review the materials I have provided for this study. This will allow me to make any corrections, changes, or additions to the study's portrayal of my experiences. I understand that I will maintain the right to revoke this consent at any time during the study without cause. I also agree to be audio recorded for the purpose of this study.

Participant (Print Name)

Participant (Sign Name)

Date

Interviewer (Print Name)

Interviewer (Sign Name)

Date

Appendix G

Life with an Implanted Cardioverter Defibrillator (ICD)

Hawai'i School of Professional Psychology at Chaminade University of Honolulu

Emergency Contact Information

As a researcher, one of my top priorities is your safety and welfare. I would like to obtain the contact information of the person you would like to be contacted in the case of an emergency. I would also like to obtain the number of your treating physician. I will only contact these individuals in the event you are sick, or unable to contact this person yourself. The nature of our relationship and your participation in this study will remain confidential.

I, _____ (Participant), will allow Shantha McKinlay (Researcher) to contact the named emergency contact at the phone number provided in the case of an emergency.

Emergency Contact (First & Last Name): _____

Relationship: _____

Phone Number: _____

Alternate Phone Number (Optional): _____

Physician's Name: _____

Physician's Phone Number: _____

Participant (Print Name)

Participant (Sign Name)

Date

Interviewer (Print Name)

Interviewer (Sign Name)

Date

Appendix H

Life with an Implanted Cardioverter Defibrillator (ICD)

Hawai'i School of Professional Psychology at Chaminade University of Honolulu

Community Resource List (Oahu)

Throughout your participation of the study you will disclose and discuss personal experiences. As a researcher, your well-being and safety are one of my top priorities. I encourage you to seek your own mental health provider should you feel the need. I have also provided a list of different community health centers and the contact numbers for the crisis line. Please contact any of the following resources if you begin to experience any distress.

Community Mental Health Centers:

Pearl City Clinic
860 Fourth St.
Pearl City, HI 96717
808-453-5953

Wahiawa Counseling Center
910 California Ave.
Wahiawa, HI 96786
808-621-8425

Diamond Head Clinic
3627 Kilauea Ave. #408
Honolulu, HI 96816
808-733-9260

Kalihi-Palama Clinic
1700 Kanakila Ave.
Honolulu, HI 96817
808-832-5800

Makaha Clinic
84-1440 Farrington Hwy.
Waianae, HI 96792
808-697-7880

Kaneohe Clinic
45-691 Kealahala Rd.
Kaneohe, HI 96744
808-233-3755

Crisis Line:

24-hour Access Line
808-832-3100 (Oahu) or
1-800-753-6879

National Resources (Online):

American Heart Association Support Network
<https://supportnetwork.heart.org/>

Mended Hearts
<https://mendedhearts.org/>

Mental Health America
<http://www.mentalhealthamerica.net/>

PaceMaker Club (Online Support Group)
<https://www.pacemakerclub.com/>

Appendix I

Life with an Implanted Cardioverter Defibrillator (ICD)

Hawai'i School of Professional Psychology at Chaminade University of Honolulu

Final Informed Consent and Release of Information Form

I _____ (participant), hereby authorize Shantha McKinlay to submit the following information collected in the course of my participation in the study indicated above, in partial fulfillment of her requirements for the Clinical Research Project and the Doctor of Psychology degree in Clinical Psychology, through the Hawai'i School of Professional Psychology at Chaminade University. I hereby indicate that I have made the necessary corrections, additions and retractions to my interview transcripts and have reviewed the narrative and/or analysis Shantha McKinlay has constructed from my story for accuracy.

I hereby authorize the use of these materials as part of Shantha McKinlay's Clinical Research Project. I also authorize the use of the highlighted quotes in the final write-up to illustrate the perspectives/themes they are being used to represent.

Hawai'i is a small community. I recognize that there is the possibility that individuals might be able to identify me despite the use of a pseudonym. Knowing this, please check all that apply:

- ☐ I would like to remain anonymous and use the pseudonym agreed upon earlier in the study.
☐ I would like to use my real name for this study.
☐ I would like copies of the study data, including the audio recordings, transcripts, and study write-up.

My signature below indicates that I am an adult, 18 years of age or older. It indicates that for the contents of the initial consent protocol have been reviewed with me again, that the nature and intent of the study, as well as my rights as a participant have been reviewed so that I may refresh my memory of the issues reviewed in the original informed consent procedure. I am aware that I may still withdraw from the study at any time and withdraw the information I have shared as a participant without negative consequences from the researcher. This Clinical Research Project will be published and made available electronically by the Chaminade University Library. There also might be future opportunities to present this study at a professional conference. Shantha McKinlay will collaborate with me at that time regarding the findings she would like to present. I understand the material reviewed and agree to the conditions specified now that I know what I am specifically contributing to the study. I have been informed that the tapes, transcripts and, analysis for this class project will be maintained for three years, until August 26, 2022 in the event that other researchers have questions regarding the findings.

Participant (Print Name)

Participant (Sign Name)

Date

Interviewer (Print Name)

Interviewer (Sign Name)

Date

Appendix J

Life with an Implanted Cardioverter Defibrillator (ICD)

Hawai'i School of Professional Psychology at Chaminade University of Honolulu

Confidentiality Agreement for Peer Debriefers/Peer Examiner/Auditor

As a member of Shantha McKinlay's research team, one of my priorities is to uphold and protect the confidentiality of the participant in her study. The nature of the information in the audiotapes and transcripts I will be reviewing may be personal and sensitive and must be kept confidential in order to protect the privacy of the participant. By signing this agreement, I acknowledge the importance of protecting the participant's confidentiality and agree to protect the information contained in the audiotapes/transcripts, including the identity of the participant. The responsibility to maintain the confidentiality of the participant extends throughout the duration of the study and even after the study has been completed.

I _____, have accepted the responsibility of reviewing the audiotapes/transcripts for Shantha McKinlay's research project in order to perform my duties as a member of her research support team. I understand that these audiotapes and transcripts contain personal and confidential information. I understand that during the course of the study, I will be provided with hard copies, a password protected emails or data storage device containing transcripts or coded transcripts for review. Any hard copies generated while performing my duties will be stored using a double lock system (in a filing cabinet in a locked office). All hard copies of data will be surrendered to the researcher. While in my possession, I accept responsibility for keeping the documents secure. When in my possession, I agree that when not in use, I will keep audiotapes, transcripts, and other documents being reviewed in a locked filing cabinet in a locked room to which I only have access to. No copies of these materials will be retained by me during or after the study. I will not save any documents to my hard drive or computer. I understand the importance of keeping all audiotapes and transcripts secure and confidential. I will not release these tapes or transcripts to, and will not discuss their contents with, anyone other than the researcher, Shantha McKinlay.

I have read the terms and conditions of the confidentiality listed in this document. By signing this agreement, I agree to protect the identity of the participant in the study. I also agree to keep all audiotapes and transcripts secure and agree to protect the personal and sensitive information contained in these materials.

(Print Name and Role)

(Sign Name)

Date

Interviewer (Print Name)

Interviewer (Sign Name)

Date

Appendix K

Life with an Implanted Cardioverter Defibrillator (ICD)

Hawai'i School of Professional Psychology at Chaminade University of Honolulu

Scripts for Audio Recording

I intend to use the following scripts for turning the recorder on and off to give the participant clear notification each time the recorder will be turned on and off.

Confirming Safety of Interview and Confidentiality (Phone/FaceTime/Skype interviews)

"Are you in a quiet space in which you are free of interruptions?"

(Wait for verbal approval of participant.)

Turning Recorder On

"Thank you for taking the time to talk with me today. Our meeting today will be about one to one-and-a-half hours long with breaks as needed. Just let me know if you need one at any point. Let's get started. Are you ready for me to start recording our conversation?"

(Wait for verbal approval of participant.)

"Okay. Just as a reminder, I want you to know that if you feel the need to speak off the record, you may do so at any time without any negative consequences. If you would like to speak off the record, you may let me know that you would like me to stop recording. At that time, I will stop the recorder and only begin recording again once you have stated that you are ready to do so. I will now press record so we can get started."

(Press record and begin.)

Turning Recorder Off

"Thank you for sharing your experiences with me today and for taking the time to speak with me. I think we covered a lot today and we are now about ready to end the interview. Are you ready for me to stop recording?"

(Wait for verbal approval of participant.)

"Okay, I am going to stop the recorder and that will conclude our interview for today. Thank you!"

(Press stop.)

Off-Record Discussions

(Participant states that he or she would like to speak off the record.)

"Sure, no problem. I am going to turn off the recorder and I want to remind you that whatever you share with me off the record will not be part of the data."

Turn off the recorder. Attend to off-record discussion, and ensure safety of the participant. Utilize Community Resource List should the participant be experiencing feelings of distress and consider taking a break or discontinuing for the day as needed.

(Participant shares that he or she is ready to being recording again.)

“Okay, are you ready for me to start recording our conversation again?”

(Wait for verbal approval from participant.)

“I am going to press record on the recorder and we can begin again.”

(Press record and begin.)

Appendix L

Life with an Implanted Cardioverter Defibrillator (ICD)

Hawai'i School of Professional Psychology at Chaminade University

Coding List

Out of Left Field	
Code	Quote
Process	I was probably in the best shape of my life. I was very determined to make this... that year a successful year to be drafted to be a professional baseball player.
Process	Then I wouldn't get up. Then one of my teammates was like something's wrong and turned me over and then my eyes were back and I had like purple lips and stuff. Then they freaked out. One ran to my coach's office. Then the other ran to get our weight coaches and trainers.
Process	I wasn't fully there. I remember getting a lot of messages on my phone. I couldn't... I didn't know how to work my phone because I was so out of it. I was like... it was crazy. I was like I don't know how to open my phone.
Process	I just kinda vaguely remember them saying do you want to continue to pursue baseball and I said yes. Then I wasn't fully there. I remember getting a lot of messages on my phone. I couldn't... I didn't know how to work my phone because I was so out of it. I was like... it was crazy. I was like I don't know how to open my phone.
Process	It was scary. I was trying to remember things because they were telling me, like remembering their dog's name.

Trying to Get Back to Who I Was	
Code	Quote
A Foreign Object	I just kinda vaguely remember them saying do you want to continue to pursue baseball and I said yes.
A Foreign Object	One day it's just my body and the next day I'm having to think about something in my body.

A Foreign Object	What is this foreign object in my body?
Too Fast	Emotions were so high that a lot of the decision was based off emotion. Everyone was scared. We almost lost him, so duh, put it in because if it happens again... it was based off of fear. I feel like I was robbed of that decision. Not saying that it was the wrong decision.
Too Fast	It made me think of so many dark thoughts that... I wasn't prepared for it.
Positive Figures	
Coach	He treated me like I was still Iron Man. He was like I don't care what happened to you, I'm gonna treat you the same. And that was probably one of the best things that could have happened to me at that time was just to be treated normally. And for it to come from a certain authoritative figure was very important to me.
Professor	That kinda gave me a lot of encouragement that, hey I can do this. And it wasn't just about me getting the grades to finish my schooling, but it was more so to keep believing in myself and what I have in front of me.
Physician	I was done with it. I just couldn't wrap my head around it. I was trying so hard to live with it and be okay with it, but I wasn't and I wanted it out. I was determined to meet this new cardiologist and tell him to take it out.
Physician	And he was like look, when you look in the mirror look at yourself like a car. You have a dent in your car, but the car still works perfectly. You have no restriction on life. You can do whatever you want. This is just a dent in your car and it's just there to help you. That was the most real conversation I've had with a medical professional like... it was awesome.
ICD Recipients	I felt like I was connecting and relating which is cool, you know, because I could relate with her, but at the same time I was like man, I have a harder time connecting like this with someone who is my age.
ICD Recipients	It's different when someone knows what you're going through because they've experienced it. It holds a different weight to how much it means.
Escape from Reality	Baseball then became my way of escaping reality of living with a defibrillator. My need to just wanna be back to normal from having a defibrillator and having something that made me look different, that made me feel different... to having something that made me feel like I wasn't whole enough to be on my own and live... it was filling a void. Playing baseball, for me, was filling the void of everything that living with a defibrillator comes with. It fulfilled my need of feeling normal because what was normal to me was being an athlete.
Escape from Reality	Nothing's changed, but clearly everything's changed.

Freedom Abroad	It was very healing to be away from everything, from everyone that I knew. So that was very healing, but I was still like very conflicted inside with having a defibrillator. I was having identity issues like... I felt very less of me.
Stress and Stress Relief	I always have it in the back of my head: Am I gonna do something in my physical exertion that will make my heart beat go way too fast or something? Am I gonna get to a place where my heart is gonna stop again and this defibrillator is gonna act?
Stress and Stress Relief	Everyone without an ICD won't ever know, but it's just something that I have to deal with. So in that sense, it's normal for me.
Stress and Stress Relief	I freak out if I'm gonna like move it in a certain way, you know. So I'll wake up in the middle of the night sometimes like and I'll like turn around because I'm like, you know, kinda afraid.
Stress and Stress Relief	Being able to be physical and, specifically for my life, do something that I love to do physically also reminds me each day that I can still do what I want to do in this life.
Stress and Stress Relief	When you go through a life or death situation you're really just grateful to be alive so you're just like... are we both alive? We're good... leave it at that.
Stress and Stress Relief	Your heart starts racing sometimes, you get into a panic mode and then I start to get into the thought, "Okay, what is this going to do to the ICD? How is my heart going to be affected?" That's where I shut down. Being in a relationship is hard in that sense because when relationships do get hard then the anxieties come up and then I'm thinking about my heart and ICD. Not about the relationship.
Rest	It has become routine to make sure that I get the rest that I need to be able to enjoy.
Rest	Life goes really fast sometimes. That's when it is harder to come by rest. That's when sometimes it can get really bad and hard to cope.
How Other People Show Care	
Teammates	In my mind, I'm like you're the last person that needs to tell me what I need to do or can't do because I've lived with this for 7 years now and you have no idea. So that... I have to really pick and choose the depth in which I go into sharing with people. I also have to pick and choose when I allow myself to hear someone else and let it affect me or kinda just brush it off and ignore it.
Teammates	I don't have time to think about that kind of fear or what I can or can't do because I know what it's like to let that consume my thoughts because it did for a while, in the beginning and it just brought me to a bad place
Two Extremes	
Uncertainty	
Blood Clot	We went to the hospital and it turned out I had a blood clot and they were like yeah you need to go on immediate blood thinners right now. That was the start of like just... total... everything shifted inside of me. I really like... I was so down. The team doctor was like your career is done for good now.

Suicidal Ideation	I would go to sleep praying that I would not wake up. Then I would wake up thinking why am I still wake. There was a lot of days and nights like that. Pretty rough time. That period is when everything started to hit me. Everything.
Suicidal Ideation	So many days I wanted to rip it out. I don't know... then I would go crazy and want to kill myself.
The Device at Work	
Do I Know How to Live with an ICD?	I don't even know if there's any way to say that I've mastered what it's like to live with an ICD. Yeah it's been 7 years, but do I still know how to live with an ICD? I have no idea!
Do I Know How to Live with an ICD?	Are they gonna come out with new types of ICDs? Smaller ICDs? More comfortable ICDs? When my battery dies, how do I... when I replace it... it just seems really complicated and I don't want to impose any burdens like that to someone.
Plan B	Every year it's like I'm preparing to go do this. I have to make sure, cross my fingers, that everything's gonna go well. I've learned to adapt and I've learned to live with it. I know my threshold, my limit, of what I can do in a day.
Plan B	He or she may be 21 years old. I know a 10-year-old boy that got a defibrillator because he went into sudden cardiac arrest, you know. That keeps me going to keep playing so that he can see that he has a whole life ahead of himself and having a defibrillator can't stop him from doing anything. That's the same freedom you had before the defibrillator because when you get one in you wrestle with the thought of your limitations and what normal is and my normal has now changed.
Plan B	The journey of really discovering me and what I needed to heal emotionally, mentally, spiritually, physically... I guess pointed in the mental health counseling direction.
Plan B	Whether it's a medical issue or you've dealt with something traumatic. It can pose a threat to your daily normal life that can also disrupt your normal flow and relationships.
Sharing My Story	
Interviews	Sharing my story is something that I've always done since I knew it was something that would help me heal and kinda keep me going. I always try to help others understand where I was so maybe that they kinda understood the reason why I would act a certain way that wasn't how I usually would act from before.
Interviews	I would also kinda just deal with it, with the emotions that would come with sharing.
Church	I was going through the process of putting the pieces together. It was the first time that I was opening up to anyone and putting it on paper, talking to people. And they were telling me you should say this and this and I was like that doesn't make sense. Anyway, it got to the point where I realized I wasn't ready to share. That also kinda showed me... I realized that I was not okay.

Church	I needed just a safe community to be around. That's what I needed. I was able to like really just process through everything bit by bit, every little detail of what happened and I could do it on my terms.
Church	I was just an emotional wreck and I felt like I could just be that emotional wreck.
Romance	In the beginning I couldn't get to a place to even open up to be open to a relationship because I was guarding so much. So each time I tried I became more open.
Romance	I guess there's a parallel in that the more I learned about myself and the more I processed and healed and faced my reality, it would become easier to talk about it.

Advice	
Code	Quote
Emotional-Follow Up	Obviously there is a healing process physically that needs to happen, but there's also an emotional process. Physically, we go in to make sure every year we're good... to make sure the lead and the device are good, but there's no follow up on your mental or emotional well-being.
Supportive and Patient	It is really not telling how that person should deal with it or how that person should cope with having an ICD, but letting that person express everything, every emotion they're having about having it. One day they may feel hopeful and grateful for having it, but another day they may just absolutely want to destroy it.
A Safe Place for Expression	Just make sure you have a safe place where you can fully express what you're dealing without having to feel that the other person needs to understand. There's not a lot of people who are young that have ICDs so not a lot of people are going to understand. If you do find someone that can relate to you then that's goal because there isn't a lot. If you don't have anyone at the time don't expect others to get it. Just make sure you know that you have somewhere safe to be able to express.