

**Exploring the Experience of Living with an
Implantable Cardiac Defibrillator (ICD).
A Heideggerian Phenomenological Study.**

A Thesis Submitted for the degree of PhD to the
National University of Ireland, Galway

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Declaration

I, the Candidate, certify that the Thesis is all my own work and that I have not obtained a degree in this University or elsewhere on the basis of any of this work.

A handwritten signature in black ink that reads "Orla Noonan Sweeney". The signature is written in a cursive style with a large initial 'O'.

Signature: Orla Noonan Sweeney

Abstract

Sudden cardiac death has been identified as one of the principal causes of death in Europe and America. According to the American heart association (AHA) statistics, sudden cardiac death is responsible for more deaths annually than the total number from stroke, lung cancer, breast cancer and acquired immunodeficiency syndrome (AIDS). Thousands of these cardiac deaths occur daily and are secondary to life-threatening cardiac arrhythmias. In Ireland, approximately 10,000 people die from cardiovascular disease (CVD) annually. In an attempt to prevent the onset of sudden deaths many of these patients are offered implantable cardiac defibrillators (ICDs).

The aim of the study was to explore the lived experience of people living with an implantable cardiac defibrillator (ICD). Guided by an interpretive qualitative approach underpinned by Heidegger's interpretive phenomenology, in-depth interviews were conducted with 27 ICD recipients (13 males and 14 females) aged between 22 and 78 years.

In the context of Heidegger's philosophical focus, the key themes revealed were 'Being Supported and Informed' 'Being Towards Death' and 'Being on a Journey of Acceptance'. These findings revealed that individuals were 'living with an alien' which threatened their mortality. Acceptance of this 'alien' emerged as an overarching theme relative to participants' life worlds (lived body, lived relations, live time and lived space). For some participants, social structures impacted negatively on their individual social capital and served as a barrier in accessing services and supports, thus, restricting their ability to accept and live with an ICD.

The study findings offer a rich illumination of this phenomenon and have the potential to inform healthcare professions in supporting individuals following ICD insertion and policymakers in future developments in cardiac services.

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Dedication

To my wonderful parents Jack (24/06/1924-29/09/1997) Maisie
(19/03/1933-10/03/2021).

Thank you for your guidance, love, kindness, support, and wonderful
memories.

"We shall find peace. We shall hear angels; we shall see the sky sparkling
with diamonds"
Anton Chekhov

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List of Acronyms

AHA	American Heart Association
ANP	Advanced Nurse Practitioner
AVID	Antiarrhythmic versus Implantable Defibrillator
BsR	Brugada Syndrome
CASH	The Cardiac Arrest Study Hamburg
CASP	Critical Appraisal Skills Programme
CIDs	Canadian implantable defibrillator study
CSO	Central Statistics Office
CVD	Cardiovascular disease
DOH	Department of Health
ESC	European Society of Cardiology
GCP	Good Clinical Practice
GOV	Government of Ireland
HIC	Health Insurance Authority
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IACR	Irish Association of Cardiac Rehabilitation
IAEM	Irish Association for Emergency Medicine
ICD	Implantable Cardiac Defibrillator
IHF	Irish Heart Foundation
LQTS	Long QT Syndrome
NICE	The National Institute for Health and Care Excellence
NUIG	National University of Galway
SQTS	Short QT syndrome
WHO	World Health Organisation

The Layout of the Thesis

The thesis is arranged into eight chapters.

Chapter one, the introductory chapter, provides an overview of the study, the aims and objectives, the study context, and background on the indications for an implantable cardiac defibrillator (ICD).

Chapter two is a review of relevant qualitative research relating to experiences of living with an implantable cardiac defibrillator (ICD).

Chapter three, the methodology chapter frames the study within an interpretivist/constructivist paradigm and explicates the interconnections between phenomenology and hermeneutics, with particular attention on Heidegger's hermeneutic phenomenology.

Chapter four presents the research methods utilised, outlining the sampling strategy, data collection, analysis, rigour and ethical considerations.

Chapter five focuses on revealing the phenomenon of interest and outlines the process undertaken in analysing and interpreting the data guided by Ricoeur's Theory of Interpretation as an analytical framework.

Chapter six presents the phenomenological findings of participants' experience of living with an implantable cardiac defibrillator (ICD) in the context of Ricoeur's (1981) interpretive phase of naïve understanding.

Chapter seven provides a critical discussion of the findings in the context of relevant supportive research and theoretical literature.

Chapter eight presents the significance of the findings and the study's unique contribution to knowledge. This chapter also presents the

conclusion, strengths and limitations and provides recommendations for future research, practice and policymaking.

Chapter One: Introduction

1.1 Introduction

This chapter will provide an overview of the study, including its rationale, aims and objectives. An introduction on sudden cardiac death, the history and indication for implantable cardiac defibrillators (ICDs), and finally a brief evaluation of studies pertaining to the phenomenon being explored are presented.

1.1.1 Title of Study

Exploring the experience of living with an implantable cardiac defibrillator (ICD). A Heideggerian phenomenological study.

1.1.2 Aims of this Study

The core aim of the study was to explore the experience of living with an implantable cardiac defibrillator (ICD).

1.1.3 Objectives of this Study

The specific objectives were to:

- Understand the experience of living with an ICD from the participant's emic perspective
- To illuminate or reveal the participants' meaning of living with an ICD.

1.1.4 Research Methodology

An interpretive phenomenological methodology underpinned by Heidegger's philosophy was chosen as the approach to meet the study's objectives, as it assisted the researcher in gaining a deeper understanding of human beings' rich experiences.

1.2 Rationale for the Study

Whilst extensive research has been undertaken in several countries pertaining to ICD, little still is known about the life of those who are living

with an ICD. Several studies have highlighted the difficulties that individuals experience and how it impacts physically, psychologically and socially (Carroll and Hamilton, 2008; Dunbar et al., 2009; Sears et al., 2005a).

Several recommendations address the physical aspects of living with an ICD, but few exist nationally or internationally to address the psychological and social aspects of living with an ICD (Al-Khatib et al., 2018; Conelius, 2016; Heidbuchel and Carre, 2014; Lambert et al., 2017; Pandey et al., 2017).

Globally, there is an increasing number of patients having an ICD implanted with approximately 250,000 ICDs in use (Irish Association for Emergency Medicine (IAEM), 2014). Nationally, there are approximately 2000 people with ICD's in Ireland (O' Sullivan, 2018). Therefore, it is crucial that a thorough understanding is achieved on what life with an ICD is like. Findings can highlight participant's needs and inform those involved in forward planning of services.

This study will also contribute to the already existing body of knowledge but from the Irish context. Overall, it remains important that healthcare professionals are aware of patients' experience in Ireland to plan and provide an effective equitable healthcare service.

1.3 Personal Objective

Whilst undertaking this study, I explored my own personal knowledge and beliefs related to living with an ICD. It was important as a researcher to address my personal and professional views to elucidate my rationale for undertaking the study. Having spent several years working as a staff nurse in a coronary care unit and later as a clinical nurse specialist in cardiac rehabilitation, I recognised that this particular group of individuals had many concerns. Whilst I acknowledged that this was a life-changing event for many individuals, I noted that each responded differently, and I was curious to ascertain why. People with ICDs were seldom referred to the

cardiac rehabilitation service. They were discharged from the hospital within a number of days without follow up. I was interested in exploring their experiences to reveal what the experience was genuinely like.

As I was interested in understanding participants' entire experience from their emic perspective, phenomenology was chosen as the appropriate methodology. Taking into consideration the researcher's extensive cardiac background, suspending any previous knowledge and pre-understandings would prove difficult, therefore Heidegger's phenomenological approach was deemed most suitable.

1.4 The Irish Context

Ireland is an island divided between the Republic of Ireland and Northern Ireland which forms part of the United Kingdom. This study has been conducted in the Republic of Ireland. The Republic of Ireland has an estimated population of over 4.88 million people (Central Statistics Office (CSO), 2012). Health service delivery remains the responsibility of the government and is managed by the Health Service Executive (HSE). The HSE administration is divided into four regions, namely, HSE Dublin Mid-Leinster, HSE Dublin North-East, HSE South and HSE West (Health Service Executive (HSE), 2007).

Funding is allocated to the HSE department annually based on an agreed service plan which prioritises services for that year (HSE, 2019a; Ruane, 2010). Delivery of health services is a mixture of public-private and voluntary care. It is primarily financed through taxes with 45% of the population having private insurance (Health Insurance Authority (HIC), 2018; Lansdowne, 2012). Residents in Ireland are entitled to receive free healthcare in the public health care system, including maternity care and children's healthcare until the age of six (HIC, 2018). Patients who are not eligible for a medical card must pay fees for particular services. All citizens are entitled to purchase private health care insurance that is partially owned by the government. However much of the private care is provided in public hospitals (HSE, 2007). This can prove problematic from an equity and

efficiency stance (Nolan, 2006). Benefits of private health insurance internationally are associated with earlier access to appropriate care and better health outcomes (Institute of Medicine (US), 2002). Services are categorised into acute care, primary care and community care (Department of Health (DOH), 2010). In the past, the Irish healthcare system was lingering well behind its European counterparts in their funding of health (Freysson, 2011). In recent years considerable investment has been allocated to health, services have expanded, and statistics demonstrate that mortality rates have improved (DOH, 2018).

Life expectancy has increased by 2.4 years from 2005 to 2018 which is now above the EU average, and mortality rates continue to decrease (DOH, 2018). As a growing population, many pressures are borne relating to health. It is predicted that in the next 10 years there will be more people over the age of 65 years living in Ireland than under the age of 14 years (DOH, 2018). This prediction will impact considerably on the provision of health, placing increasing demands on many services (DOH, 2018).

Despite the many successes, there remain aspects of health that require improvement. It is important to ensure the right patient receives the right service at the right time with an emphasis on prevention and health initiatives (DOH, 2019a). Many areas remain sparsely populated and geographically isolated. There is diversity in the delivery of health care offered to individuals living in rural areas in contrast to those residing close to large urban regions (DOH, 2010; Eberhardt and Pamuk, 2004; Government of Ireland, 2021). It is recognised that there are currently geographic variations in health delivery; depending on where you live there is limited availability to some services (DOH, 2010). It remains difficult to measure if patients are entirely satisfied or benefiting from the advances in services in the Irish health care setting. However, recent patient satisfaction surveys have been conducted nationally to establish patients' level of satisfaction with services (HSE, 2019b). Reports have also been published and task groups set up to implement current recommendations by the Health Care Executive in an attempt to address identified inequalities in the health

care system (DOH, 2019). These are outlined below to provide further context on healthcare in Ireland

1.4.1 The Irish National Inpatients Experience report 2019.

The Irish National Inpatients Experience report was published in 2019, as a result of a nationwide survey (Flynn et al., 2017) which requested patients to provide feedback on their hospital experience (HSE, 2019b). The survey was conducted in partnership with the Health Information and Quality Authority (HIQA) the Health Service Executive (HSE) and the Department of Health. The report is part of a larger programme that aims to improve healthcare services to patients in Ireland. Nationally, 40 hospitals participated with 26,897 invited to partake, and 12,343 patient respondents.

Some areas for improvement were identified mainly concerning patient transfer and discharge from hospital. The majority of respondents reported positive experiences with services generally; however, 38% reported that they did not have enough time to discuss their treatment with doctors. Most respondents reported they were treated with respect and dignity, but a number reported they could not always understand the explanations about their condition and treatment. Although patients felt they were provided with privacy for examinations they felt they were not offered enough time for further discussion. The HSE uses the results to develop quality improvement plans nationally for hospital groups. The Department of Health will use the results to inform policy decision making and HIQA uses the feedback to monitor standards and quality.

1.4.2 Advanced Nurse Practitioners (ANP)

One of the main focuses for healthcare in Ireland is on primary and secondary prevention (McCreery et al., 2013). In an attempt to address this the Department of Health (DOH) has injected funding into education and training for the role of Advanced Nurse practitioners.

International evidence recognises the contributions of Advanced Nurse Practitioners (ANP) to healthcare services given their specialist knowledge

and qualifications (DOH, 2019b). In July 2019, the Minister for Health in Ireland, launched a new model for developing advanced nursing and midwifery practice, following the publication of the new policy ‘The Development of Graduate to Advanced Nursing and Midwifery Practice’. The Minister emphasised that Nursing and Midwifery have a key role to play in implementing the Sláintecare health reform programme (DOH, 2019b).

An independent evaluation of the policy implementation ‘The Development of Graduate to Advanced Nursing and Midwifery Practice’ (2019) was commissioned by the office of Nursing and Midwifery Services Director (ONMSD), HSE led by University College Cork (UCC) and Trinity College Dublin (Brady et al., 2020). The purpose was to examine the impact of the role of the Advanced Nurse Practitioner (ANP), particularly relating to key indicators surrounding access to services, waiting lists, unnecessary hospital admissions, improved patient flow and early discharge from hospital. The findings noted that the increased number of ANP roles is having a positive impact on patient outcomes, particularly in areas of patient education. Patients revealed high levels of support and improved quality of life (Brady et al., 2020). The implementation of this role matches the recommendations of the Sláintecare report in relation to integrated care.

1.4.3 The Sláintecare Action Report 2019

The Sláintecare action report (2019) outlines the milestones proposed for health from 2019- 2029 (DOH, 2019a). There are five interrelated elements in the Sláintecare report: population health; entitlements and access to healthcare; integrated care; funding; and implementation (Burke et al., 2018). Sláintecare aspires to deliver health and social care services to the population that is fair and transparent by ensuring that services are available and accessible to the growing population (DOH, 2019a). However, many service users regardless of ability to pay have to travel long distances to avail of specific services. Therefore, it is challenging for the Government to provide a system that is fair and transparent to all. Policy decisions are

difficult, there will always be winners and losers (Weintraub, 2003), as the supply of resources is scarce, and the demand will continue to rise.

In Ireland, ICDs are implanted within the majority of university hospitals, and many are discharged home within a few days. No structured cardiology support services for ICD recipients exist outside of large urban areas. Specialised services and support groups are located in Dublin which is challenging for individuals residing outside of this location. There is also a lack of other services including an efficient public transport service in rural areas. This creates additional problems following the implantation of an ICD with the imposed driving restrictions which can result in being unable to drive from 1 month to 6 months (James, Albarran Tagney, 2001; Vijgen et al., 2010). Therefore, for many, having access to a car is viewed as a necessity rather than a luxury.

1.4.4 Our Rural Future-Rural Development Policy 2021-2025 (Enhancing development in rural Ireland)

Government funding has been allocated to address inequalities and diversity relevant to rural living. The rural development policy, 'Our Rural Future'- signifies a five-year National blueprint plan, post COVID-19 recovery (GOV, 2021). This framework is a vision to transform the quality of life and opportunities for individuals living in rural locations

Based on an earlier report in 2019 by the Central Statistics Office (CSO, 2019), it was noted that there was a disparity between rural and urban dwellers in relation to the distance for everyday services (GP's and pharmacies). As a result, the Government have committed to improving access to services in rural areas, which include community health, transport and highspeed broadband. The HSE intend to deliver 96 new community healthcare networks to support people to live in their community. Improved digital technology is planned as part of the solution, transforming how people assess and engage with health care services, including access to specialist services. Digital models such as virtual clinics are proposed to provide and promote care closer to home, to improve access, reduce waiting

lists, and reduce the time and expense incurred with travel. The implementation of the recommendations in this Government report will assist to address the inequalities in services and enhance the quality of life for patients living with implantable defibrillators in rural locations (GOV. 2021).

1.5 Cardiovascular disease (CVD)

Cardiovascular disease (CVD) is the leading cause of death globally each year (World Health Organisation (WHO), 2017). CVD accounts for 635,260 deaths annually in the United States of America, and according to 2016 American Heart Association data, someone dies on average every 38 seconds (Benjamin et al., 2019). In Europe, 3.9 million deaths and 1.8 million in the European Union are attributed to CVD (Wilkins et al., 2017). In Ireland, approximately 10,000 people die from CVD annually (Irish Heart Foundation (IHF), 2018; Health service executive (HSE), (2010), this is estimated as 33% of all deaths (McCreery et al., 2013).

It has been estimated that 40% to 50% of cardiovascular deaths are secondary to sudden cardiac deaths (Mehra, 2007). Sudden cardiac death has been defined as an unexpected death that occurs within one hour from the onset of symptoms (Fernández-Falgueras et al., 2017; Margey et al., 2011) in the absence of any other cause. Sudden cardiac death is referred to as one of the principal causes of death in America and Europe (Mauro, 2008a). According to American Heart Association (AHA) statistics, sudden cardiac death is responsible for more deaths annually than the total number from stroke, lung cancer, breast cancer and acquired immunodeficiency syndrome (AIDS) (Benjamin et al., 2019; McDonough, 2009; Mozaffarian et al., 2016). Thousands of these cardiac deaths occur daily and are secondary to life-threatening cardiac arrhythmias (Sossong, 2007). In Ireland, it is estimated that approximately 5000 die annually from sudden cardiac death (Jennings, 2010). In an attempt to prevent the onset of sudden deaths many of these patients are offered implantable defibrillators (ICDs) (Boriani et al., 2019). Prevention of sudden premature cardiac death is the prime purpose of the ICD (Fluur et al., 2013; Hazelton et al., 2009;

Mathuria, 2020), and mortality rates have reduced over the past twenty years with the treatment of the ICD (Berg et al., 2015).

1.5.1 The Implantable Defibrillator (ICD)

The Implantable Cardiac Defibrillator (ICD) is an electronic device developed by Michel Mirowski following the sudden death of a friend in the 1960s (Glikson and Friedman, 2001). Mirowski wondered how his friend's death could have been prevented and if it was possible to implant a defibrillator into the body to convert arrhythmias as they occurred. Thus, his project began, and the first ICD was implanted in the USA 1980s. The ICD comprises of three parts: a pulse generator and one or two leads for defibrillation and pacing and electrodes which are found on each lead (DiMarco, 2003). The ICD device is enclosed in a small titanium case which contains several electronic components i.e., a capacitor to store charges, memory and battery. Its function is to monitor and treat ventricular arrhythmias as soon as they occur, and can be programmed to deliver up to six shocks during the same episode if it detects that the rhythm has not been converted successfully. The device generator is located under the skin and is attached to leads that carry information from the heart to the ICD; this enables it to record the heart's function. The ICD can provide pacing if the heart beats too fast or too slow or deliver a high-energy shock if it detects life-threatening arrhythmia.

There have been considerable advances in the technology of ICDs in the past decade with the development of cardiac resynchronisation therapy with a defibrillator (CRT-D) the subcutaneous ICDs and more recently the wearable ICD offers an alternative approach (Cheung, Olgin, and Lee, 2020; Chung, 2014; Magnusson et al., 2019; Mathuria, 2020; Rosenkaimer et al., 2020; Sharma, 2017). The European Society of Cardiology guidelines notes that subcutaneous ICDs can help prevent sudden cardiac death (SCD) (Priori et al., 2015). A subcutaneous defibrillator is an option to the transvenous device when a transvenous device is contraindicated (Kempa, Budreiko and Raczak, 2016). It is implanted in patients who require an ICD, not cardiac pacing, nor anti-tachycardia pacing or resynchronization therapy

(Piori et al., 2015). The extrathoracic positioning of the subcutaneous ICD avoids entering the heart and vasculature unlike the transvenous device (Knops et al., 2020).

The CRT-D is used in individuals with heart failure who may be at risk of a life-threatening arrhythmia (Calvagna et al., 2014; Kawata et al., 2019; Lawin and Stellbrink, 2019; Nauffal et al., 2017). It consists of a biventricular pacemaker and an ICD. The biventricular pacemaker resynchronises the ventricles to prevent them from beating asynchronously. The ICD component works like any other ICD by delivering a shock. The subcutaneous is similar to the internal ICD; however, the leads are placed under the skin rather than into a vein. This is a less invasive procedure and is only suitable for select patients (Cappelli et al., 2014). The wearable ICD is an external device used to detect and defibrillate ventricular tachycardia and ventricular fibrillation (Horiguchi et al., 2020) it does not have a pacing component for bradycardias. The monitoring electrodes are worn on the chest held in place by an elastic belt. The defibrillator electrodes are worn on a vest (Epstein et al, 2015; Sharma, Bordachar and Ellenbogen, 2017; Sperzel, Hamm and Hain, 2020).

1.5.2 Increase in Device Implantation

Implantable cardiac defibrillator use has increased significantly worldwide in the last 30 years (Carroll McGillion. and Arthur, 2014; Calvagna et al., 2014; Tagney, 2010) with 250,000 in use in 2015 and an estimated 1.5 million implanted annually (Palasubramaniam et al., 2020; Raatikainen et al., 2015). The Irish Heart Foundation has estimated that around 2000 people have an ICD in Ireland (Irish Heart Foundation (IHF), 2016). The rate of device implantation is attributed to the ageing population and the expanding indications (Raatikainen et al., 2015) or as a result of the many trials that support their efficacy (Carroll, McGillion and Arthur, 2014). In more recent decades, many advances have been made in the field of technology. However, it is argued that although technology has been devised to improve physical health it can place difficulties on an

individual's daily life, due to an underlying fear of provoking a discharge from the device (Palacios-Cena et al., 2011a).

1.5.3 ICD Indications

The ICD is implanted mainly to prevent premature sudden cardiac death. Patients have implantable defibrillators implanted for primary or secondary prevention (Palacios-Cena et al., 2011a). Primary prevention refers to the prevention of sudden cardiac death in persons who do not have a previous history of sustained ventricular tachycardia or cardiac arrest. Secondary prevention refers to the prevention of sudden cardiac death in individuals who have survived an earlier sustained ventricular tachycardia or cardiac arrest (Epstein et al., 2015). Particular inherited cardiac conditions such as cardiomyopathy (dilated heart muscle), long QT syndrome (inherited heart rhythm abnormality) and Brugada syndrome (heart's electrical system is abnormal), leave individuals more at risk of developing an arrhythmia therefore the ICD is implanted as a precaution.

Figure 1.5 outlines a graphic representation of the heart's electrical activity. Diagram (A) Electrocardiograph (ECG) outlines the heart's normal conduction and the association with the action potentials of the cardiomyocytes of the hearts muscle. The P wave represents depolarisation of the right and left atria relating to atrial contraction. The QRS complex represents the spread of the electrical impulse throughout the ventricles signifying ventricular depolarisation. The T wave represents ventricular repolarisation. Diagram (B) normal ECG in black, Long QT syndrome (LQTS) in red (Left), Short QT syndrome (SQTS) in middle red and Brugada syndrome (BrS) in right red. Diagram (C) represents normal action potential in black, epicardial action potential prolongation in red (left), action potential shortening in SQTS (middle red) and transmural gradient between the epicardial action potential (right solid red line) and endocardial action potential in BrS (right broken red line) (Giudicessi and Ackerman, 2012).

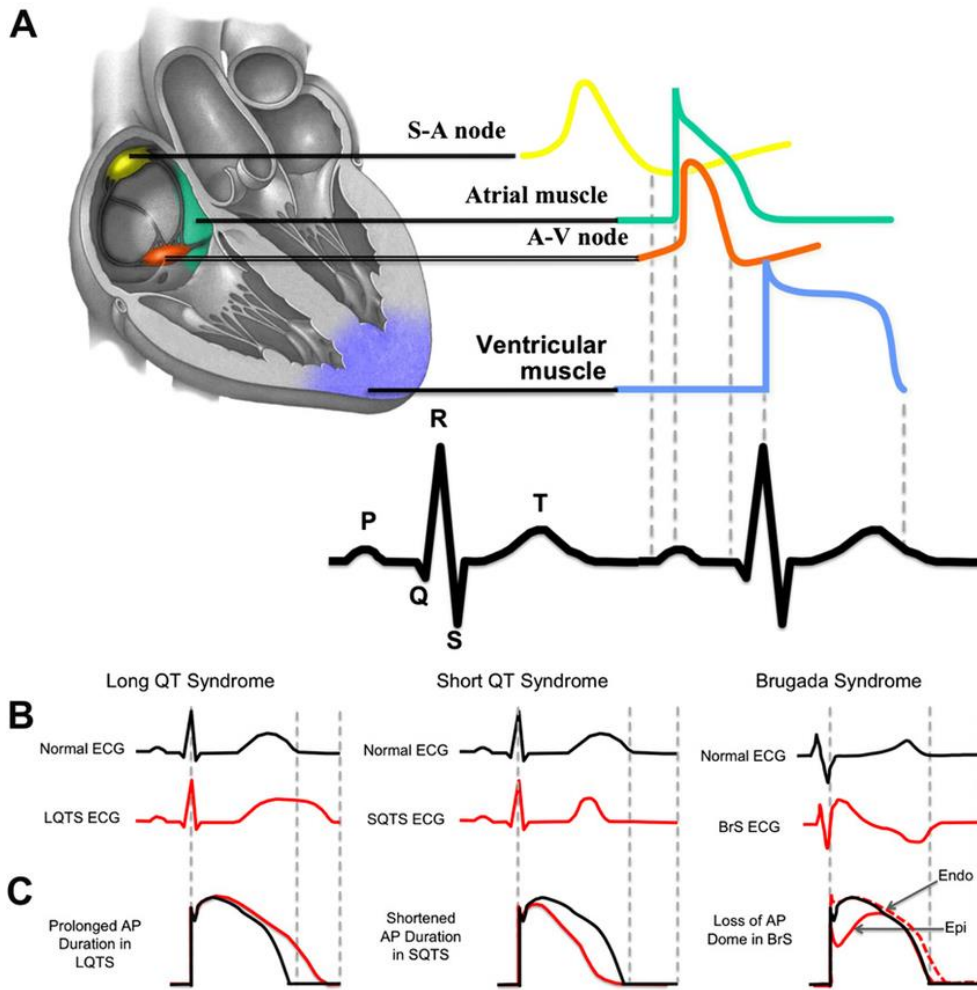


Figure 1.5 The Heart's Electrical activity: Adapted from Giudicessi and Ackerman (2012)

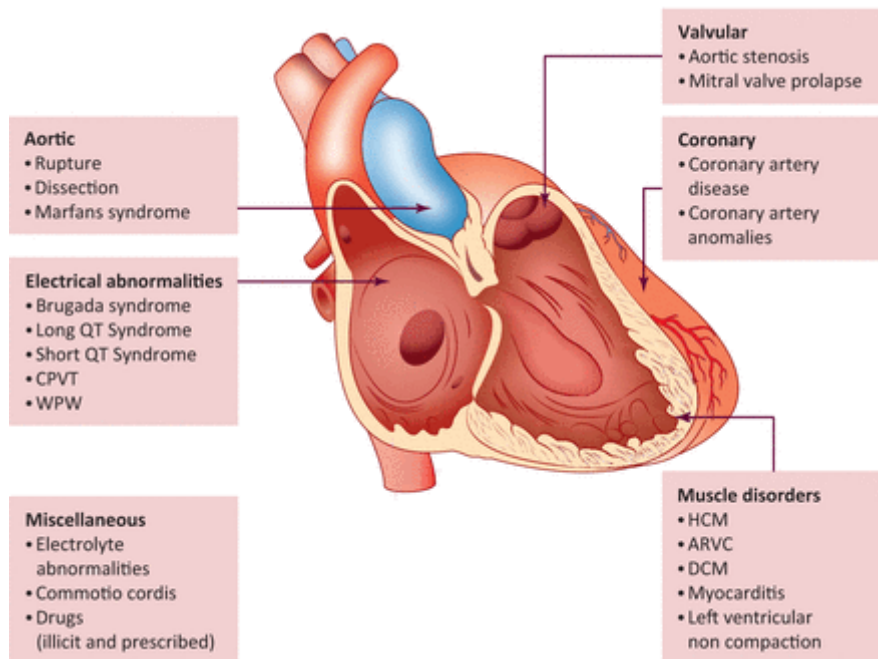


Figure 1.6 Causes of Sudden Cardiac Death; Adapted from Merghani, Narain, and Sharma (2013)

There are many causes of these above-mentioned conditions including, genetic, familial, acquired, autoimmune and cardiovascular disease. Dilated cardiomyopathy is one of the world’s most common cardiomyopathy. It causes dilatation of the left or both ventricles of the heart affecting its ability to contract effectively (Jefferies and Towbin, 2010; Weintraub, Semsarian and Macdonald, 2017). Channelopathies develop due to defects in ion channels caused by genetic or acquired factors (Behere and Weindling, 2015; Kim, 2014) and can affect the heart’s electrical system. The main Channelopathies associated with sudden cardiac death are Brugada syndrome, catecholaminergic polymorphic ventricular tachycardia, long QT syndrome; short QT syndrome is a genetic disorder that can cause fatal arrhythmias (Manual and Brunger, 2016).

Brugada syndrome is a genetic disorder that causes an abnormality to the heart’s electrical activity leading to ventricular arrhythmias resulting in sudden cardiac death (Alreshidi and Winokur, 2018; Kusumoto et al., 2017).

The only proven effective treatment that prevents sudden cardiac death is the implantation of an ICD (Alreshidi and Winokur, 2018; Dizon and Nazif, 2015). Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT) is a rare cardiac condition that is characterised by an abnormal heart rhythm. It is estimated that one in 10,000 people have the disease in Europe (Leenhardt, Denjoy and Guichency, 2012).

Long QT syndrome is a condition affecting the heart's electrical system. The electrical activity is controlled by the flow of ions in and out of the cell's sodium such as potassium, calcium and chloride. The QT on the electrocardiogram represents the length of time it takes for the electrical impulse to travel through the ventricles, causing a wave of contraction followed by recharge. Long QT syndrome occurs as a result of a defect in the flow of ions within the cells increasing the risk of malignant ventricular arrhythmias. Lifestyle modification, beta-blockers and ICD are important in the management of these patients (Shah, Park and Alweis, 2019).

1.5.4 Effects of Receiving a Shock from the Device

The ICD works by delivering a shock to the individual when a life-threatening arrhythmia is detected, however, this can cause considerable distress for the patient. This may be due to the uncertainty of an arrhythmia occurring or fear of receiving a shock or perhaps due to being aware of having an underlying cardiac disease. Morkin et al., (2012) postulated the importance of obtaining knowledge and information to reduce the fear of a shock. Not alone do individuals experience challenges living with the ICD, their families also have issues, principally uncertainties and helplessness associated with the shocks (Van den Broek et al., 2010). Despite the benefits of the ICD, it remains stressful for some recipients (Morkin et al., 2012). Not everyone who has an ICD implanted receives a shock, but many do and there is no guarantee when it may occur or how often. Individuals may modify their behaviour to avoid an unpleasant outcome or adverse event, for instance, a shock, and they may decide to tailor their exercise to reduce the risk of developing a tachycardia (Dunbar et al., 2012).

1.5.5 Psychological Adjustment

A plethora of evidence recommends the use of ICD's for individuals with life-threatening arrhythmias for primary prevention (Carroll et al., 2013). Significant mortality benefits are associated with their use (Dunbar et al., 2012) with the prevention of sudden death ranking highest. For some individuals, the device may be positive as it allows people to resume as normal a life as possible (Hazelton et al., 2009). But this is not the case for everyone. Mauro, (2008a) highlights that the ICD has managed to decrease mortality but is associated with major psychological adjustment and can remain a source of uncertainty for many. Even though it offers individual mortality benefits it may provoke psychological change with the recipients (Dunbar et al., 2005; Sears et al., 2008). Mauro (2010) investigated uncertainty and psychological adjustment in implantable defibrillators recipients over a two-year period and concluded that recipients should initially be assessed to ascertain their levels of psychological distress before device implantation so that early appropriate interventions can be commenced.

The European Society of Cardiology and other societies have issued a number of guidelines in recent years to assist healthcare professionals to select the appropriate management strategies for individuals with ventricular arrhythmias and sudden cardiac death (Priori et al., 2015). It is recommended that all hospitals implanting ICDS adopt these guidelines, particularly concerning end-of-life discussion and recommended antiarrhythmic treatment. However, there still remains gaps in patients' understanding and the information they receive leading to considerable distress and anxiety for many (Hill et al., 2018).

A structured cardiac rehabilitation exercise and education programme could assist in addressing many of the above psychological and information needs. The Irish Association of Cardiac Rehabilitation IACR (2013) guidelines acknowledge that cardiac rehabilitation is recommended in patients with cardiac implantable defibrillators (McCreery et al., 2013). Findings from the COPE-ICD randomised clinical trial noted significant improvements in

overall general health at 3, 6 and 12 months in ICD patients attending cardiac rehabilitation (Berg et al., 2015).

However, these patients are seldom referred for exercise and cardiac rehabilitation in fear of inappropriate shock or perhaps ignorance of the safety and benefits (Iliou et al., 2016). The safety and effectiveness of cardiac rehabilitation can be poorly understood (Steinhaus et al., 2019).

1.5.6 Time to Adjust

Some studies have addressed the time of adjustment to the ICD device, with one suggesting a timeframe of three months (Kamphuis et al., 2004). The greatest uncertainty for recipients is reported in the first two months and is more evident in younger adults (Mauro, 2008a). Similarly, another study has reported on the anger, uncertainty, and disappointment experienced in the first six months following insertion (Kamphuis et al., 2004). However, it is also reported that a longer time frame for adjustment is needed, and patients find the first year physically and psychologically complex (Dougherty et al., 2016).

Other studies also report high levels of anxiety and depression among adults with ICDs (Bilge et al., 2006; Freedenberg Thomas and Friedmann, 2011; Rahman et al., 2012; Schulz et al., 2020) which can impact on their future, their families and quality of life (Kamphuis et al., 2004; Pedersen et al., 2004). Some individuals suffer fear and anxiety in anticipation of receiving a shock from their device (Morkin et al., 2012). Palacios-Cena et al., (2011a) reported in their systematic review that men and women shared similar feelings towards their ICD, concerning anxiety uncertainty and fear of shocks. Women, however, appeared to have more reservations about body image. Johansson and Stromberg (2010) identified similar issues and highlighted that females perceived a loss of independence and altered body image. In a recent literature review focused on patients' concerns related to body image (Frydensberg et al., 2018), it was found that this issue is more prevalent in women and younger patients, however, some men also reported concerns related to body image. Consideration of alternative device implant

techniques is advised as this could reduce scarring and reduce concerns relating to body image ultimately leading to an improvement in patients' quality of life (Sowell et al., 2006).

1.5.7 Psychosocial Adjustment

Uncertainty and anxiety about the future and employment are also reported by people who have had an ICD implanted (Carroll et al., 2010; Dunbar, 2005; Flemme et al., 2010; Mauro, 2008a; Mauro, 2008b; Mauro, 2010). Fear of the future following implantation with loss of earnings which can lead to financial hardship can be common. Anxiety and worries due to driving restrictions and how this will affect work and family life also arise (James Albarran and Tagney, 2001; Jongejan et al., 2018; Vijgen et al., 2009). Another area that causes concern is fear of disruption to sexual relations with partners due to the uncertainty of receiving a shock. Partners may be wary of sexual intercourse fearing it may instigate a shock resulting in less frequent intimacy, partners may find difficulty discussing these sexual intimacy issues (Hazelton et al., 2009). Recovery can be slow and challenging post ICD, and this can impact significantly on those who provide support (Dougherty et al., 2016; Eckert and Jones, 2002).

Driving restrictions also affects patient recovery and demands significant lifestyle adjustment (Jongejan et al., 2018). Moreover, patients are reported to change their driving habits because of the uncertainty of getting a shock while driving (Johansson and Stromberg, 2010). Another problem arising post ICD implantation is that driving privileges may be withdrawn (Priori et al., 2015). This is associated with loss of independence and freedom (Kamphuis et al., 2004), and can lead to feelings of anger and resentment and contribute to loss of earnings and work (James Albarran and Tagney, 2001; Tagney, James and Albarran, 2003). Regulations and laws vary within Europe concerning driving restrictions for those individuals with ICDs. New recommendations were introduced in 2009 by the European task group in response to the recognised implications associated with these bans for individuals and their families. Driving bans were reduced for recipients of ICDs for secondary prevention to 3 months from 6 months and in primary

prevention reduced to 4 weeks (Vijgen et al., 2010). However, a recent study reports that patients do not comply with these driving restrictions (Jongejan et al., 2018), but this could be attributed to necessity based on geographic location.

1.5.8 Education and Information

Many patients continue to lack understanding of the function of their device which adds to feelings of fear and anxiety following hospital discharge post-implant. Patients' attitudes and perceptions about ICDs appear to be connected to their understanding of their underlying disease (Haugaa et al., 2018; Yuhas et al., 2012). Some studies identified that individuals were not adequately informed to make the appropriate decision about consenting to get an ICD. Carroll et al. (2014) explored patients' (n=44) decision making when offered an ICD and found that they were not well informed and that their decision making was mainly influenced by fear of sudden cardiac death and trust in the healthcare professional. They recommended that patients needed to understand the functions of the ICD when making an informed decision regarding implant. In another study, Yuhas et al. (2012) investigated patients' decision making perceptions and barriers to primary prophylaxis of an ICD and found that although several patients understood the rationale and recognised the benefits, they were also adamant that they did not want any life-prolonging procedures. A need for more education is evident.

Twenty-two patients were enrolled in a pilot randomized control study to evaluate the feasibility of a brief educational intervention administered two weeks after ICD (Lemon, Kirkness and Edelman, 2007). Thirteen were randomised to attend the intervention group and nine were allocated to the standardised group. While no significant improvements were found in stress, anxiety and hostility between both groups and participants did not improve psychologically in the short period, they did benefit from the educational component which led to an improvement in their measured quality of life. Moreover, older participants in this study felt the device was a good option for younger individuals wishing to prolong their life (Lemon,

Kirkness and Edelman, 2007). An Irish retrospective cohort study (Groarke et al., 2012) conducted at two-implant centres assessed patients' (n=75) understanding of the ICD, patients who had been educated during consent pre-ICD implantation were enrolled on the study. The results demonstrated that patients had a number of misconceptions and lacked awareness of the indications and functions of their devices despite receiving information and education. This highlights the need for improved approaches to bridge the understanding gap.

The need for nurses to provide psychological support and education to individuals and their families at each outpatient visit so that they may confidently cope with living with the ICD is highlighted by a number of authors (White, 2000; Flemme, Johansson and Strömberg, 2012). One possible means of addressing individuals' uncertainties might be to ensure nurses working with individuals with an ICD have supportive communication (Flemme, Johansson and Strömberg, 2012). Supportive communication refers to having regular contact and support from a qualified health professional following discharge from the hospital through either phone calls or social media. This could result in positive outcomes such as decreased anxiety and increased perceived control and a reasonable quality of life (Flemme, Johansson and Strömberg, 2012).

1.5.9 Cardiac Registers

There is no available specific register in Ireland that provides public information relating to standards or patient-related outcome measures. There is however a national registry maintained by Heart Rhythm Ireland for implanted cardiac devices (Heart Rhythm Ireland, 2008). This was established in 2008 to produce accurate statistics on Irish implant rates. Data from 38 hospitals on approximately 30,000 patients have been collected. Information recorded includes patient demographics, physician report on implant procedures, details on device-serial numbers and technician follow up reports. Data is entered electronically daily; however, it is not currently published or available publicly. Nonetheless, anonymous statistical

information is provided to device manufacturers quarterly (Hearth Rhythm Ireland, 2008)

In addition, during 2004, the Department of Health and Children collaborated with the European Society of Cardiology, the Irish Cardiac Society and the European Commission to create standards for concerning clinical cardiology for percutaneous coronary intervention (PCI), clinical electrophysiology (EP) pacemakers, implantable defibrillators and ablation procedures throughout Europe. This was known as the Cardiology Audit and Registration Data Standards (CARDS) project which compiled existing registries and survey data into one large matrix (Flynn et al., 2005). The role was to produce standardised data of less than 100 variables reflecting current treatment guidelines, clinical care of patients, service planning and epidemiology and could also be used for audit. This resulted in draft standards formally adopted at an EU conference in Cork in 2004, with the European Society of Cardiology (ESC) agreeing to act as a steward. Most European countries found the standards relevant and were interested in adopting them, however, there were challenges relating to staff resources and IT management. It was recommended that providers of cardiology software and hospital information systems should be contacted and facilitated to utilise the data system in their systems (Flynn et al., 2005).

In Europe, data is collected via The European Heart Rhythm Association (EHRA) White Book, which is an important source of data on invasive electrophysiological procedure (EP) rates in the European Society of Cardiology member countries including Ireland. Information on cardiac arrhythmias has been collected by the EHRA for approximately a decade. It provides key quantitative and descriptive information concerning rates of procedure, vital statistics, demographics, and healthcare resources. (Arribas et al., 2012). The White Book has noted a number of disparities in arrhythmia management and recommends the implementation of current clinical practice guidelines. The White Book also provides a strong foundation to address the disparities and improve management strategies (Raatikainen et al., 2016).

In the United States of America (USA), The American College of Cardiology ICD registry was launched in 2005, now known since April 2021 as the EP Device registry. This is the national standard for understanding patient selection, care and outcomes for patients with an ICD. The registry assists healthcare physicians' decision making by providing nationally benchmarked information related to care and outcomes (ACC, 2021).

Although there are a number of registries pertaining to cardiology available in the United Kingdom (UK), United States of America (USA) and Europe (EU) the researcher was unable to locate an Irish registry that offered open access to cardiac device implants. Whilst UK (Pitcher et al., 2016), EU (Priori et al., 2015), USA (Al-Khatib et al., 2018), and The National Institute for Health and Care Excellence (NICE), 2014) guidelines are available to guide clinicians' practice in relation to the treatment of patient's cardiac arrhythmias and ICD, there are no standardised Irish guidelines relating to cardiac arrhythmias available. There are however the Irish Association of Cardiac Rehabilitation (IACR) guidelines available that highlight the benefits for patients participating that have an ICD (McCreery et al., 2013). Currently, there is work underway nationally to devise ICD guidelines from an Irish context, particularly focusing on the end of life and cardiac devices.

1.6 Overview of Research

There is a considerable body of research about ICD's, and most are quantitative in approach with a focus on the quality of life. A number of qualitative studies have been carried out in other countries, namely in Denmark (1), England (1), Japan (1), Iran (1), Italy (1) Oman (1), Netherlands (1), Norway (1), Singapore (1), Spain (2), Turkey (1), and USA (5). These studies are discussed in chapter two and to the researcher's knowledge, research relating to the patient's experience of living with an ICD in the republic of Ireland has not hitherto been undertaken.

Researchers have given considerable attention to investigating the efficacy of ICDs (Carroll and Hamilton, 2005; Carroll and Hamilton., 2008; Dougherty et al., 2016; Flamme et al., 2005; Friedmann et al., 2006; Haugaa et al., 2017; Sears et al., 2011; Rahman et al., 2012). A number of these studies were conducted in the 1990s and early 2000s and are mainly quantitative (Dougherty, 1995; Dunbar et al., 1999; Edelman, Lemon and Kidman, 2003; Flemme et al., 2001; May et al., 1995).

1.7 Conclusion

This chapter has provided an introduction to the research question, a background of the Irish context and an introduction into sudden cardiac death, indications and an overview of research evidence. The following chapter will present a comprehensive critique of the qualitative literature around ICD.

Chapter Two: Review of the Literature

2.1 Introduction

This chapter will present an overview of the clinical trials demonstrating the efficacy of ICD's and a critical review of the qualitative literature concerning experiences of living with an ICD. It also highlights the step by step approach undertaken by the researcher to complete the search for literature.

Many clinical trials and cohort studies have demonstrated the efficacy of ICDS for primary and secondary prevention. These include primary prevention trials such as the Multicentre Automated Defibrillator Implantation Trial (MADIT 1, 1996) which included 30 centres in the U.S.A and two in Europe (Moss, 1997). The follow-up Multicentre Automated Defibrillator Implantation Trial (MADIT II, 2002) included 71 centres in the USA and five in Europe involving 1,232 patients (Moss, Daubert and Zareba, 2002). Both trials concluded that patients with a previous myocardial infarction and advanced left ventricular dysfunction were at risk of ventricular arrhythmia and recommended prophylactic implantation of a defibrillator to improve survival. The defibrillator in non-ischaemic cardiomyopathy treatment evaluation (DEFINE) trial was a multi-centre trial conducted in the USA which compared medical therapy versus the ICD (Kadish et al., 2004). Patients were enrolled with left ventricular dysfunction due to cardiomyopathy (n=458). The study concluded that patients with severe, non-ischaemic dilated cardiomyopathy implantation of a cardiac defibrillator significantly reduced the risk of sudden death from ventricular arrhythmia (Kadish et al., 2004).

The EU-CERT-ICD Multicentre Cohort study enrolled patients (n=2327) in 44 centres in 15 European countries with ischaemic or non-ischaemic cardiomyopathy on optimal therapy and assessed the effectiveness of primary prevention ICD therapy (Zabel et al., 2020). The results

demonstrated that the ICD was associated with a 27% lower mortality with no benefit to survival in older or diabetic patients.

In secondary prevention trials, the Antiarrhythmic drugs versus Implantable Defibrillator (AVID) trial (McAnulty et al., 1997) was conducted in the USA and enrolled patients (n=1,016). The study noted that an ICD is more effective than antiarrhythmic drugs in preventing death from cardiac arrhythmias. In addition, the Canadian implantable defibrillator study (Connolly et al., 2000) recruited from a number of centres, 19 in Canada (n=632), 3 in Australia (n=13), and 2 in the United States (n=14) and involved patients resuscitated from ventricular tachycardia and fibrillation, randomised to an ICD group or an amiodarone (antiarrhythmic drug) group. The study concluded that the ICD was superior to amiodarone supporting the findings to the AVID study that the ICD is a more effective treatment than antiarrhythmic drugs (Connolly et al., 2000; Domanski et al., 1999). The Cardiac Arrest Study Hamburg (CASH) trial (Kuck et al., 2000) conducted in Hamburg, Germany (n=288) included patients who experienced a cardiac arrest or life-threatening ventricular arrhythmia (VA) and compared an ICD to anti-arrhythmic drug therapy, primarily amiodarone versus metoprolol. The results of these trials were consistent demonstrating that the ICD reduced the rate of arrhythmic mortality.

Although trials can demonstrate the efficacy and benefits contributing to mortality, they cannot provide an understanding of the lived experience for those living with an ICD. Therefore, it is necessary to explore from a qualitative perspective to gain a greater understanding of what the experience is like for individuals with an ICD. Through this approach, health care professionals gain a better understanding of ICD recipients' needs and can tailor the care they provide to target their specific needs.

Therefore, for the purpose of this focused review, only qualitative studies, qualitative reviews and mixed-method studies were included in the search. The decision to review qualitative materials is linked with the researcher's ontological stance reflecting the interpretivist paradigm that the subjectivity of the human reveals their subjective truth. From a subjectivist

epistemological perspective, the researcher viewed reality as an expression of people's interpretation and meaning of their world and lived experience in that world. Thus, in reviewing qualitative materials for this review the ontological and epistemological viewpoint was that an individual's lived experience shapes their meaning and knowledge of their world. Eliciting that meaning was viewed as an imperative in reviewing the qualitative literature and the interpretations it revealed with regard to living with an ICD.

Using a 'population, exposure, outcome' (PEO) tool (see table 2.1), a search of the literature was conducted using electronic databases to explore the experience of living with an ICD. A search tool is used as an organising framework to devise a search strategy that lists terms and key concepts (Methley et al., 2014). The PEO tool is used widely in nursing and health care qualitative research to assist with the breakdown of research questions (Doody and Bailey, 2016; Butler et al., 2016), (and helps to identify a question's key concepts and develop an appropriate search.

Table 2.1 Key Terms Identified and Boolean Operators

Population	Exposure	Outcome [PM1]
Patient*	IMPLANTABLE DEFIBRILLATOR * 'OR'	Experience Reactions 'OR'
Service user	CARDIAC IMPLANTABLE DEFIBRILLATOR * 'OR'	Behaviour 'OR'
	ICD* 'OR'	Perceptions 'OR'
	AICD* 'OR'	Views 'OR'
	Automated internal cardiovertor defibrillator	Opinions 'OR'
		Thoughts 'OR'
		Attitudes 'OR'
		Beliefs
		ACCEPTANCE 'OR'
		ANXIETY 'OR'
		FEAR

The following table (2.2) outlines the exclusion and inclusion criteria.

Table 2.2 Exclusion and Inclusion Criteria

Inclusion	Exclusion
Studies using both a qualitative data collection method and qualitative analysis (including the qualitative component of mixed-method studies).	Quantitative studies focusing on scientific/surgical/medical aspects of ICD implantation and management Blogs, magazines, newspaper articles.
Population over the age of 18.	Paediatrics/ articles not specifying age.
Literature published between 2004-2019.	Literature published before 2004
Articles that focused on patients/recipients' experience of living with an ICD, as told by them.	Patients' experience as perceived by healthcare practitioners.
English language	Non- English language

2.1.1 Studies Eligible for Inclusion

The purpose of specifying inclusion and exclusion criteria enabled the researcher to narrow and filter the search, build a more focused search strategy, thus limiting the retrieval of irrelevant data (Willis & Dalrymple, 2019). Studies eligible for inclusion were those that qualitatively investigated patients' experiences, views, attitudes to and perceptions of living with an implantable cardiac defibrillator. Initially, no date restriction was imposed. Qualitative research was defined by the Cochrane qualitative methods group (Noyes et al., 2010) as using both a qualitative data collection method and qualitative analysis. Quantitative studies were therefore excluded. Mixed method studies were included if the qualitative component used had an explicit qualitative data collection method and a qualitative analysis process. Boolean phrases were used to refine the search;

this allowed the researcher to combine AND OR and NOT to produce more appropriate results.

The search was conducted at the end of 2019, limited to studies published in English from 2004 to 2019 in peer-reviewed journals and 81 articles were identified. Publications were further screened by abstract and title for those including lived experience, views and perceptions. The studies not addressing the inclusion criteria were excluded (see table 2.2) and 26 articles remained. The full texts of these studies were reviewed and those not identifying lived experiences, views or perceptions were excluded and any duplicates discarded, resulting in 16 remaining studies.

The following table (2.3) outlines the databases searched and the articles retrieved.

Table 2.3 Chosen Databases with Results Following Limiters

DATABASES	INITIAL SEARCH	LIMITERS The YEAR 2004-2019	LIMITERS qualitative	Reviewed	Final total
EBSCO (CINAHL, Medline, PsycINFO),	10407	818	72	21	15
Psychology and Behavioural Sciences,		21	0	0	0
Cochrane Library (Wiley) and Science Direct		4	0	0	0
SCOPUS		957	45	14	8
PUBMED	2349	431	41	18	18
Google Scholar	18,400	14,300	114	21	16
WEB Of KNOWLEDGE		58	7		7
EMBASE		31	1	1	1
CINAHL			70	9	9
				Total	16

2.2 Qualitative Appraisal

There are several recognised quality appraisal tools for qualitative research, however, no consensus to which is preferable (Landa, Ssali and Stokka, 2016; Morken, Severinsson and Karlsen, 2010), and therefore for the purpose of this study the principles of the Critical Appraisal Skills Programme (CASP) were used. A critical appraisal was carried out using the CASP checklist (Critical Appraisal Skills Programme, 2018) on all the selected studies (see appendix1). Critical appraisal is an unbiased systematic approach used to assess the quality and relevance of evidence presented in the published literature (Bolse, 2009; Pinchbeck and Archer, 2020) and provides a systematic objective assessment of the evidence. The CASP tool is suitable for all types of qualitative studies and contains ten questions, however, does not contain a scoring system (Butler et al., 2016). The selected studies had no or minor methodological limitations.

2.3 Thematic Analysis Framework

Themes across the included studies were identified as suggested by Sandelowski and Barroso (2003) and Sandelowski, Barroso and Voils (2007). The selected articles for the review were critically analysed with relevant findings extracted and patterns and themes devised. Thematic analysis is a process of identifying themes and patterns in qualitative research (Maguire and Delahunt, 2017). This method has been referred to as one of the most powerful approaches in social sciences as it offers a clear and easy to use framework for conducting thematic analysis (Maguire and Delahunt, 2017). As recommended by Noyes et al. (2018), regardless of the type of review or synthesis, best practice proposes the extraction of contextual and methodological information for inclusion in a table. Therefore, for the purpose of this study, a data extraction table was used to report on all the studies reviewed (see appendix 2).

2.4 Findings

A limited number of qualitative studies concerning the experience of living with an ICD were retrieved (Abbasi et al., 2016; Bolse et al., 2005; Conelius, 2015; Flanagan, Carroll and Hamilton, 2010; Garrino et al., 2018;

Kamphuis et al., 2004; Humphreys et al., 2016; McDonough, 2009; Mert, Argon and Aslan, 2012; Morken, Severinsson and Karlsen, 2010; Ooi et al., 2018; Palacios- Ceña et al., 2011b; Palacios- Ceña et al., 2011c; Pasyar et al., 2017; Saito et al., 2012;). Moreover, one qualitative evidence synthesis (Zayac and Finch, 2009), and one mixed-method study (Pedersen et al., 2017) were also included in the review.

Three of the studies were gender-specific and a global perspective on the topic is evident with studies undertaken in Denmark (1), England (1), Japan (1), Iran (2), Italy (1), Netherlands (1), Norway (1), Singapore (1), Spain (2), Turkey (1), and USA (5). No study undertaken in an Irish setting was found.

The studies were conducted between 2004 and 2019, included both male and female participants aged between 18 and 84 years. The participants had their ICD implanted for a period of 1 to 10 years. One of the major limitations identified was the dominance of male participants across many of the studies (Garrino et al., 2018; Humphreys et al., 2016; Kamphuis et al., 2004; Mert, Argon and Aslan, 2012; Morken, Severinsson and Karlsen, 2010; Ooi et al, 2018; Palacios- Ceña et al., 2011b; Palacios- Ceña et al., 2011c; Pedersen et al, 2017; Saito et al., 2012). Moreover, only ten of the studies reviewed included the lower age of 18 years (Conelius, 2015; Garrino et al., 2018; Humphreys et al., 2016; McDonough, 2009; Mert, Argon and Aslan, 2012; Morken, Severinsson and Karlsen 2010; Palacios- Ceña et al., 2011b; Palacios- Ceña et al., 2011c; Pasyar et al., 2017; McDonough, 2009).

Study sample sizes varied from 3 to 22 participants with a total of 245, excluding 21 participants from the qualitative review. A variety of methodologies was used, including descriptive phenomenology and grounded theory. Across the studies, some similar themes were identified pertaining to psychological, physical and social concerns (Humphreys et al., 2016; Kamphuis et al., 2004; McDonough, 2009), and one study reported

contextually unique findings relating to childbearing and childrearing (McDonough, 2009).

Some studies also identified gaps concerning education and informational support (Mert, Argon and Aslan, 2012; Ooi et al., 2018). Supporting individuals living with the device was a central thread across the identified themes, which included a level of knowledge concerning the device, physical and social restrictions, communication and psychosocial adjustment, including fear and anxiety relating to getting a shock and security and acceptance. (Abbasi et al., 2016; Bolse et al., 2005; Conelius, 2015; Garrino et al., 2018; Humphreys et al., 2016; Kamphuis et al., 2004; Ooi et al., 2018; Palacios- Ceña et al., 2011b; Palacios- Ceña et al., 2011c).

2.5 Psychological Issues

Several studies highlighted the psychological issues associated with living with an ICD (Abbasi et al., 2016; Humphreys et al., 2016; Ooi et al., 2018; Zayac and Finch., 2009), including the fear, anxiety and depression following device implantation (Conelius, 2015; Kamphuis et al., 2004; Humphrey et al., 2016; Saito et al., 2012). However, some studies also reported on the positive benefits of living with an ICD (Abbasi et al., 2016; Conelius, 2015; Ooi et al., 2018) including accepting it as a guardian lifesaving piece of technology and adopting a healthier lifestyle as a method of coping (Ooi et al., 2018).

Living with fear was commonly reported (Abbasi et al., 2016; Garrino et al., 2018; Zayac and Finch, 2009). Zayac and Finch's (2010) qualitative review synthesised how patients focused on the perception of fear, anxiety, support and information. The key findings suggest that fear and anxiety are common. The fear of receiving a shock from the ICD device was prominent for many recipients (Kamphuis et al., 2004). Fear was also associated with anxieties and nervousness (Pederson et al., 2017). Additional fears and concerns were voiced of passing the disease on to their children (McDonough, 2009). Furthermore, there was fear and uncertainty related to receiving a shock from the device (Saito et al., 2012), fear of dying as a

result of a shock (Humphreys et al., 2016) or dying because it may not shock (Abbasi et al., 2016).

Fear was reported to be greater during the initial phase post-implant (Kamphuis et al., 2004). While these emotions decrease over time, during the interim recipients feel restricted and increasingly reluctant to physically exert themselves for fear of causing damage, impacting on their quality of life. Fear was also dominant in a more recent interpretive phenomenological study with 13 participants (7 of whom were male) that had lived with an ICD for durations of 1 year to 120 months (Abbasi et al., 2016). The study found that recipients had major fears about facing death which contributed to concerns about the future. Concerns noted were device malfunction, pain due to a shock, challenges with the cost implications associated with the device i.e., attending appointments, limitations of living with the device, loss of control and concerns about the future. Some recipients feared facing death when their device discharged a shock. A recommendation arising from the study was the need for additional training, support and follow up care, recognising that education is central to promoting recipients' quality of life (Abbasi et al., 2016).

Fears have been reported to contribute to recurrent feelings of anxiety. As the ICD delivers a shock quickly without warning, individuals live with uncertainty and anxiety, leading to loss of control (Garrino et al., 2018; Morken, Severinsson and Karlsen, 2010; Palacios-Cena et al., 2011c; Ooi et al., 2018). Recipients of ICDs reveal their constant fear of everyday life, a constant sense of anxiety and fear of facing death (Garrino et al., 2018), with both younger and older recipients expressing anger at the impact the disease on their lives (Mc Donough, 2007; Kamphuis et al., 2004).

Relying on technology and coping with the adverse effects associated with having an ICD were also highlighted (Garrino et al., 2018). Additionally, concerns with doctor-patient communication were reported noting that individual needs had not been addressed. However, recipients referred to the benefits of having a remote monitoring system that clinically observed them

at a distance and provided a sense of ongoing security (Garrino et al., 2018). Additional training is called for to provide adequate information for medical and nursing professionals which would lead to an improvement in the quality of care to ICD patients (Garrino et al., 2018).

Conflicting emotions for those living an ICD are evident. Despite recipients' fear of their ICD, they also recognised the benefits and felt better with it than without (Garrino et al., 2018; Ooi et al., 2018). This sense of recipients' comfort from the device was also reported elsewhere (Bolse et al., 2005). Additionally, apprehension and appreciation were the two major themes reported by (Flanagan, Carroll and Hamilton, 2010). All participants expressed some fears and concerns, but emotions differed based on whether they had received a shock or not from the device. Those who had received a shock expressed anxiety as to when the device would shock again and feared routine activities might activate the device. Younger patients' fears correlated with loss of independence. Those who had not received a shock experienced a different type of anxiety including apprehension and worrying if the device would work if they needed it (Flanagan, Carroll and Hamilton, 2010).

Being physically aware of the ICD reminded recipients of their cardiac condition causing restricted movement and the device's position was a constant reminder (Humphreys et al., 2016). Maintaining structure and routine was therefore an important strategy for some. This was achieved by maintaining similar prior implant routines, such as attending the same shops and eating in the usual restaurants. This gave a sense of security because if they did not arrive at a venue on a day they were expected to; the staff would perhaps alert someone close to them (Flanagan, Carroll and Hamilton, 2010). Emotionally, recipients experienced periods of vulnerability and uncertainty with an increased awareness of existential concerns such as life and death. Recurrent anxiety was associated with recurrent shocks. Loss of confidence was also experienced. Avoiding activities and resigning to acceptance was (Humphreys et al., 2016).

In one study (Humphreys et al., 2016), men were found to focus more on the medical implications associated with shocks and female concerns focused on pain and being unable to work. However, both men and women suffered difficulties that led to depression and anxiety. Concealing fears and anxiety from family members was also noted to prevent unnecessary stress (Humphreys et al., 2016). This concealment from family was also reported by Flanagan Carroll and Hamilton, (2010) where participants described efforts to remain strong for family members and expressed no desire to be part of a support group, in contrast to interest in support groups in other studies (Saito et al., 2012; Bolse et al., 2005).

2.6 The Physical Restrictions of Living with an ICD

Many studies have addressed the physical implications and limitations associated with living with an ICD (Abbasi et al., 2016; Flanagan, Carroll and Hamilton, 2010; Humphreys et al., 2016; Kamphuis et al., 2004; McDonough, 2009). Issues highlighted include feelings of dizziness and weakness (McDonough, 2009), difficulty with sleeping and concerns related to body image are experienced (Pasyar et al., 2017; Mc Donough et al., 2010), restrictions with physical activity (Pederson et al., 2017), reluctance to shower and swim to avoid getting a shock from the ICD (Flanagan Carroll and Hamilton, 2010), and the uncomfortable sensation and pain when the device delivers a shock (Abbasi et al., 2016). Losing a driving licence was one of the most important factors voiced by some (Morken, Severinsson and Karlsen, 2010). These combined factors are attributed to an overall reduction in wellbeing.

Recipients are conscious when the shock is discharged (Paysar et al., 2017) and the sensation is described as a blow to the chest (Pederson et al., 2017). This is how it feels for recipients despite having been exposed to the sensation of a shock from the ICD prior to hospital discharge as it is tested routinely to allow awareness of the sensation of a shock before going home. The event can be traumatising, and some patients have expressed the desire to have a stress test following discharge in order to establish their exercise

tolerance level, which could be useful in assessing activity tolerance levels before the ICD would trigger (Pederson et al., 2017).

Participants who received one or two shocks from the ICD resulted in unpredictability and uncertainty and subsequent reduction in activities. Losing control, feelings of uncertainty and fear of a shock have been reported to be associated with reduced physical activity, and while activity increased over time, a reduced activity level persisted, even among those who were athletic before having an ICD (Morken, Severinsson and Karlsen, 2010). Having an ICD was also reported as influencing a more sedentary lifestyle with low levels of physical activity in another of the studies reviewed (Zayac and Finch, 2010). However, in one study, some felt more energetic than previously and an increase in their physical functioning (Conelius, 2015).

2.7 Social Implications Associated with Living with an ICD

Recipients referred to feeling unable to resume previous social activities, developing phobias concerning using their cell phone, leaving employment, sensing a distancing from partners and a reduction in sexual activity which impacted on relationships (Palacios-Cena et al., 2011b; Pederson et al., 2017). A fear of being alone (Morken, Severinsson and Karlsen, 2010) and feeling out of control (Morken, Severinsson and Karlsen 2010; Zayac and Finch, 2009) have been expressed. Issues with childbearing and breastfeeding were also raised (McDonough, 2009).

Concerns relating to reduced income and increased costs were also iterated (Morken, Severinsson and Karlsen, 2010; Zayac and Finch, 2009). Reduced financial income resulting in loss of independence was accentuated (Humphrey's et al., 2016). Moreover, the challenges associated with the cost of follow-up care was raised (Abbasi et al., 2016). This was especially evident among younger recipients of an ICD who referred to having out of pocket costs, having increased insurance premiums, job instability and not being able to provide for their families (McDonough, 2009).

2.8 Education and Support

Insufficient information was experienced by some recipients of an ICD (Morken, Severinsson and Karlsen, 2010; Mert, Argon and Aslan, 2012; Abbasi et al., 2016). They expressed the need for more information about how to live with their device, to see the same physician throughout their treatment when attending review appointments and having more time at these appointments (Morken, Severinsson and Karlsen, 2010). Specifically, unanswered questions about sexual activity, driving and altered memory were an issue, with one hundred and five-six (40%) of patients not being informed on how to obtain information about psychological support and information about deactivation or end of life (Pederson et al., 2017). Moreover, information in relation to ICD shocks was not adequately addressed (Morken, Severinsson and Karlsen, 2010). A lack of appropriate support from health care professionals (Morken, Severinsson and Karlsen, 2010), as well as several unmet needs related to education, information and support (Ooi et al., 2018), may explain this.

The need for a multidisciplinary approach to training has been highlighted, which could help reduce fears in the pre-implantation period that continue in the post-implantation period (Pederson et al., 2017). However, the trust held for the organisation associated with care was reported by Bolse et al., (2005) where participants were satisfied with the follow-up care believing they were treated with empathy and respect which also helped them feel less isolated. Moreover, a high level of satisfaction with the information provided was reported in one study, with only fifty-five (13%) of the patients being dissatisfied (Pederson et al., 2017).

While some recipients of an ICD valued their follow up visits to have their ICD checked and expressed a desire to meet with another who had the same experience, they had less interest in attending a support group, viewing it as a place where people came to complain (Flanagan Carroll and Hamilton, 2010). However, the need for support groups to help patients develop better coping strategies is advocated (Mert, Argon and Aslan, 2012). Women in one study indicated that they would have preferred to have

spoken with a mental health care professional post-discharge, and those who had a cardiac arrest voiced the need for psychological support post-discharge (Pederson et al., 2017).

Mixed reactions concerning family support were also reported. The overprotectiveness of family members sometimes led to dependency (Bolsa et al., 2005), with some having pushed family members away while seeking help from strangers instead (Flanagan, Carroll and Hamilton, 2010).

2.9 Learning to Live with an ICD

Conflicting views were noted across the studies concerning the experience of living with the ICD with some highlighting the difficulties adapting and accepting to the ICD while others dominated with reports on the positive aspects. Some individuals accepted the device as it provided security (Paysar et al., 2017; Cornelius, 2015), and was viewed as a lifesaver and a type of insurance policy for life to continue as previously (Palacios-Cena et al., 2011b; Palacios-Cena et al., 2011c). Others expressed a sense of being comfortable and having confidence in the future (Bolsa et al., 2005). While some did express their fear of receiving a shock, they described having the ICD as a “catch 22” situation, better to have it than not, and felt they were left with no choice and had to learn to live with it, despite it being a constant reminder that they were living on the edge (Cornelius, 2015). In a similar vein, developing coping mechanisms to accept the ICD and regain control was a theme synthesised in the qualitative systematic review undertaken by Zayac and Finch (2009).

Bolsa et al. (2005) attributed the regaining of control to the support of family, friends and healthcare professionals. The love and support from spouses and family have also been reported but strategies such as hiding symptoms to avoid causing added distress to the family is also a feature of the adjustment (Palacios-Cena et al., 2011c). The fluctuations in the adjustment path are surrounded by changes ranging from compromised self-identity to crossing the border of the unknown (Paysar et al., 2017). Recipients on an ICD must negotiate changes in body image and the

uncertainty associated with the constant expectation of the risk of a shock from the device.

2.10 Limitations of the Studies Reviewed

Whilst similar findings are evident across many of the studies, a variety of different qualitative approaches and methodologies were adopted, and some settings were context-dependent. For instance, in one Iranian study, all participants were of the Muslim community, and their cultural and religious beliefs may have influenced their perceptions of living with an ICD (Pasyar et al., 2017).

A major limitation identified across the studies reviewed was the dominance of male participants (Garrino et al., 2018; Humphreys et al., 2016; Kamphuis et al., 2004; Mert, Argon and Aslan, 2012; Morken et al, 2012; Ooi et al, 2018; Palacios- Ceña et al., 2011b; Palacios- Ceña et al., 2011 c; Pedersen et al, 2017; Saito et al., 2012). According to the Spanish ICD register, 83% of ICDs are implanted in men, therefore this could account for the male dominance in their studies (Palacios- Ceña et al., 2011b; Palacios- Ceña et al., 2011c). However, male participants' life roles can differ from their female counterparts and younger females also have childbearing concerns; therefore, women's perspectives must be considered to understand their concerns when planning care (McDonough, 2009).

In keeping with qualitative research, all the study samples were small with a sample of only three in one study (Conelius, 2015), however, ten were invited to participate. This aforementioned study (Conelius, 2015) adopted descriptive phenomenology, where very small samples are common, however, the recruitment of participants appeared to have taken place following a private clinic appointment which may have accounted for the small sample number as perhaps individuals may have had other schedules planned for that day following their appointment and could not participate as a result.

One study (Ooi et al., 2018) only included an older aged sample (all were over 50 years) therefore not representational of a younger population. The

inclusion criteria for this study was over 21 years but resulted in those aged over 50 years responding. Moreover, in this study (Ooi et al., 2018); because the length of time of ICD implantation ranged from 8 months to 10 years, the authors of the study noted that participants' memory may have faded. However, it also could be argued that any experience that causes distress and anxiety can never be fully erased from one's memory regardless of the length of time.

Another study (Humphreys et al., 2016) only included participants with partners and excluded non-partnered individuals that nursing staff identified as being too distressed. No method of data analysis was reported in one study which also only included two female participants with male participants dominating the sample (Saito et al., 2012). Finally, in one study, five different specialist nurses conducted the interviews (Morken et al., 2010). While this would influence the study's efforts to address researcher reflexivity, only three nurses were involved in the data analysis; however, this use of group analysis adds to the study's rigour. One of the strengths of the literature review is the inclusion of studies from many different countries Denmark (1), England (1), Japan (1), Iran (2), Italy (1), Netherlands (1), Norway (1), Singapore (1), Spain (2), Turkey (1), and USA (5). This allowed for greater awareness of international experiences.

2.11 Conclusion

Much of the research on this topic has been undertaken from a positivist lens, and while there have been some qualitative studies on ICD recipients' experience, no study from an Irish perspective has been undertaken. Moreover, only two of the studies reviewed in this chapter adopted a phenomenological approach. One was guided by a descriptive phenomenological approach (Conelius, 2015), following Husserl's philosophical stance, and the other adopted an interpretive phenomenological stance guided by van Manen's phenomenological approach (Pasyar et al., 2017). In addition, many of the studies reviewed were conducted on a single site. This current study, therefore, is unique in

terms of the hermeneutic approach adopted, and the inclusion of patients attending services at multiple sites.

This chapter has provided an insight into the experiences of individuals living with an ICD and highlighted the need to explore this phenomenon from a hermeneutic lens in an Irish context. By adopting a hermeneutic lens, a deeper understanding of this phenomenon is possible which will inform healthcare professionals in meeting the needs of those living with an ICD. The subsequent chapter will address the research methodology for this study and illustrate why an interpretive hermeneutic approach is the most suitable methodology to adopt. An interpretive hermeneutic approach allows for the researcher's preunderstanding to contribute to a deeper understanding of the phenomenon.

Chapter Three: Research Methodology

3.1 Introduction

This chapter outlines the methodology used to address the aims and objectives of this study. I chose the interpretive phenomenological approach grounded in Heidegger's ideals and tenets. The purpose is to demonstrate an appropriate method that reveals an in-depth understanding of the phenomenon being explored. The chapter outlines the research aims and objectives, and the conceptual framework of interpretivist/constructivist research paradigms. An overview of phenomenology is provided, including several renowned philosophers associated with the phenomenological movement, with attention to Heidegger's hermeneutic phenomenology. The final section addresses the theory behind the method applied. Finally, an exploration of Paul Ricoeur's theory of interpretation is presented as this framework was used to guide data analysis (Ricoeur, 1976).

3.1.1 Research Question

What is it like to live with a cardiac implantable defibrillator?

3.1.2 Aims of this Study

The core aim of the study was to explore the experience of living with an implantable cardiac defibrillator (ICD).

3.1.3 Objectives of this Study

The specific objectives are to:

- Understand the experience of living with an ICD from the participant's emic perspective
- To illuminate or reveal the meaning participants have of living with an ICD.

3.2 Theoretical Framework

As the purpose of this study was to gain an in-depth understanding of the lived experience of living with an ICD, a hermeneutic phenomenological

approach was considered appropriate. However, to understand the researcher's rationale for this decision, some key concepts concerning epistemology and ontology will be discussed.

3.2.1 Epistemology and Ontology

Research studies are guided by their choice of methodology which is influenced by ontology and epistemology (Scotland, 2012). Ontology interest lies with reality, the study of being, (Crotty, 1998; Kafle, 2011; Singh, 2019), and questioning what constitutes reality, "*What is*" (Scotland, 2012). Epistemology is the philosophical division concerned with the theory of knowledge, how knowledge can be communicated produced or attained, and what it means to know (Scotland, 2012). 'How we know what we know' acknowledging that knowledge within research work contributes to knowledge itself (Kafle, 2011). Paradigms are methods that bond a discipline's requirement for knowledge and its systems for generating that knowledge (Weaver and Olson, 2006).

3.2.2 Paradigms

Paradigms are arrays of philosophical underpinnings from which research approaches flow (Weaver and Olson, 2006). A paradigm is a worldview, a viewpoint on realities' complexities (Polit and Beck, 2006) which can form a link between the aims and methods in research (Houghton, Hunter and Meskell, 2012).

The term paradigm is referred to as:

"The set of common beliefs and agreements shared between scientists about how problems should be understood and addressed"
(Kuhn, 1962).

Paradigms are beliefs and practices that control inquiry within a discipline by offering lenses, frames and methods through which investigation is achieved (Weaver and Olson, 2006). Paradigms also assist and guide researchers in their search for knowledge (Pearson, Vaughan and FitzGerald, 2005). There are two distinct epistemological positions

positivism and interpretivism constructivism (Antwi and Hamza, 2015). Positivist and interpretive paradigms are concerned with understanding phenomena from two separate lenses, these been quantitative and qualitative (Cohen, Manion and Morrison, 2007), and are addressed in the following section.

3.2.3 The Positivist and Post-Positivist Paradigms

The positivist viewpoint summarises the spirit of the Enlightenment, the self-declared Age of Reason that began in the seventeenth century in England and thrived in France and continued into the next century (Crotty, 1998). This paradigm arose from a philosophy labelled logical positivism, which is formed on strict rules of logic and measurement, absolute principles, truth, and prediction (Weaver and Olson, 2006). Positivists accept that reality is objective and is measurable utilising properties and instruments which are unconnected to the researcher and the knowledge is quantifiable (Antwi and Hamza, 2015). Their primary focus with a quantitative theory is that knowledge is acquired by controlled observation, and experiments that can be measured (Merriam, 2002). Positivist researchers express in quantitative terms how variables interact, events are shaped, and outcomes are produced, developed and tested employing experimental studies (Antwi and Hamza, 2015).

Post-positivism embraces a deterministic philosophy whereby causes (probability) determine effects or outcomes (Creswell and Creswell, 2017). Post-positivism is also reductionistic in that it aims to reduce the ideas into a discrete, small set to test, which include variables that include hypotheses and research questions. The knowledge that unfolds through a post-positivism lens is based on careful measurement and observation of the objective reality that occurs "out there" in the world (Creswell and Creswell, 2017). Positivist and post-positivism research is associated with a quantitative approach to research (MacKenzie and Knipe, 2006).

3.2.4 Interpretive Paradigm

Constructivism or social constructivism (often combined with interpretivism) is mainly perceived as an approach to qualitative research (Creswell and Creswell, 2017). Constructivists believe that truth is relative and dependent on an individual's perspective (Baxter and Jack, 2008). The interpretive paradigm is founded on the epistemology of idealism, which seeks to interpret the social world (Ajjawi and Higgs, 2007). Its theory is concerned with the interpretation of existence (Miles et al., 2013). Located within the interpretivist/constructivist research paradigm, it recognises multiple constructions of reality (Charmaz, 2000). This framework supports the ontological view that believing in the existence of not just one reality, but of multiple realities that are constructed and can be changed by the knower (Laverty, 2003). The constructivist paradigm highlights an understanding of the sense individuals attribute to their actions (Weaver and Olson, 2006).

Another term occasionally used when referring to data used in this paradigm is “thick descriptive” due to the richness and description of the conversation (Jackson, Drummond and Camara, 2007). Described as endeavouring to interpret and understand the world in terms of actors (Cohen, Manion and Morrison, 2007), the interpretive researcher employs cycles of interpretation, understanding, and critique (Benner, 1994). Researchers within the interpretivist paradigm are naturalistic given that they apply to real-world situations as they naturally unfold (Antwi and Hamza, 2015). The interpretive paradigm accepts that reality is founded by individual thoughts, unique experiences on how the world is viewed (Chalmers et al., 2018). Believing that reality is socially constructed, is a consequence of the setting in which it occurs, informed by the historical, cultural, political, and social norms controlled by context and time (Darlaston-Jones, 2007). Baxter and Jack (2008) acknowledge that constructivists recognise the importance of subjective meaning but also recognise that they do not completely reject the concept of objectivity. This allows the formation of a close relationship between the participant and the researcher. Rather than using quantifiable objective methods for information

gathering, this paradigm entails listening or watching people to interpret meaning (Merriam, 2002).

3.3 Research Design for this Study

In consideration of the critique of paradigmatic perspectives, the subsequent section outlines the rationale for choosing this study's research design. The purpose of this research was to gain a deep understanding of participants' experience, therefore a qualitative approach shaped by the interpretative paradigm was adopted as this would assist achieve the study aim of exploring the lived experience of living with an ICD.

The research design used was an interpretive qualitative approach underpinned by Heidegger's interpretive phenomenology. Heideggerian phenomenology as the chosen methodology allows the researcher to explore further the participant's interpretations and gain a deeper understanding of their experience (Duffy and Aquino-Russell, 2007; Horrigan-Kelly, Millar and Dowling, 2016). The aim of applying hermeneutic interpretive phenomenology was based on Heidegger's philosophy focusing on everyday ordinariness that has the potential to expose the experience of living with an ICD on a day to day basis narrated by participants and the meaning they ascribed to this experience

The aim of the study was to understand the experience of living with an ICD and this methodology fitted well with the philosophy of an interpretive research paradigm and is keeping with the researcher's ontological and epistemological views. My choice of question was influenced by a background in nursing and extensive knowledge of cardiology. Participants' sharing of their lived experience shaped my interpretation of what the phenomenon of living with an ICD. As a researcher, it is important to examine one's own ontological and epistemological position to understand what influenced the choice of methodology (Scotland, 2012).

3.3.1 Reflexivity

Reflexivity refers to an attitude of focusing systematically on the background of knowledge formation by the researcher (Pandey and Patnaik, 2014). It is a strong force within qualitative research, as it protects the research findings from claims of lacking credibility or validity (Coolican, 2014). Reflexivity seeks to understand how the researcher's own influences may impact on the study (Cohen Manion and Morrison, 2007). This involves a process of self-scrutiny by the researcher; a self-conscious awareness of the association between the researcher and an "other" (Burke and Hohman, 2014). Steps that assist in addressing reflexivity can be achieved through the use of a reflective journal and reporting any of the researcher's beliefs and values that might influence the study. Balls (2009) support this practice, highlighting that a research diary can be helpful to reflect on interview skills. The use of a reflective diary is also supported by Baille (2015) as it can prove beneficial in creating an awareness of reflexivity. Applying these principles of reflexivity may support the researcher to develop a deeper awareness of the participant's journey and allow their story to unfold. Such self-reflection permits the researcher to track ideas, understand their own thinking and create further insights (Cleary, Horsfall and Hayter, 2014).

Reflecting on my own ontological and epistemological views whilst embarking on conducting this study led me to consider my background knowledge and personal beliefs. Qualitative researchers are challenged to explore how their experiences and beliefs influence the progression of knowledge (Dempsey et al., 2016). I recognised that as a nurse, having spent many years working in the field of cardiology I may already have preconceived beliefs. As a result, I was curious to gain an in-depth understanding of how individuals interpret the experience of living with an ICD. The story is best told by those individuals who have had the experience, rather than test a hypothesis by assuming difficulties exist.

The qualitative approach allowed the participants to convey their interpretation of their experience and the researcher the ability to develop a deeper understanding of the meaning attached to their experience. Being a novice researcher, I initially had difficulty choosing an appropriate methodology to support the aim of the study. Once this was achieved, I had to face the challenge of moving beyond a superficial understanding by reading the vast amount of literature dedicated to phenomenology which held various schools of thought. This process resulting in numerous hours of reading in an attempt to enhance my understanding concerning its philosophical roots. In addition to hours spent reading, I further enhanced my understanding from attending college lectures, supervisors' input and summer schools I attended on qualitative research; all of which I found extremely beneficial. As a result, I found myself deeply drawn to hermeneutic interpretive phenomenology as this method appeared the most suitable to reveal the phenomenon under investigation.

Within this study, findings were created through the interpretation of the knowledge acquired from participants' interviews. Interpretation is seen as crucial to the process of understanding (Laverly, 2003). Therefore, the researcher's epistemological belief supports the constructivist/ interpretive view influencing both the research topic and the methodology.

The following section will provide an overview of the study's methodology. Choosing a methodological approach to research can be challenging (Taylor and Thomas-Gregory, 2015). There are many methodological choices available when undertaking qualitative research (Gelling, 2015) and no single blueprint for naturalistic, qualitative or ethnographic research in existence just as there is not a single picture of the world (Cohen Manion and Morrison, 2007). However, although, many qualitative methods exist they have both commonalities and differences (Connelly, 2010).

3.4 Methodology

Methodology refers to the philosophical underpinning of the research (Taylor and Thomas-Gregory, 2015). Methodology's main interest is "*why, what, from where and how*" data is gathered and analysed (Scotland, 2012). For this research, hermeneutic phenomenology was chosen as the suitable methodology informed by the writings of Martin Heidegger, with Ricoeur's theory of interpretation used to guide the analysis.

3.5 Phenomenology

Phenomenology is a branch of philosophy concerned with the study of phenomena (Jones, 2001) and focuses on the essence of the experience (Merriam, 2002). Referred to as a project that is prompted by fascination: "*being swept up in a spell of wonder*", and a longing to uncover meaning (van Manen, 2007). Phenomenologists feel that the individual's account is a feature of present and past experience which lives in the present moment (LoBiondo-wood and Haber, 2006).

The term phenomenology derived from the Greek word "*phaineir*" means "to appear" and was first made public by Immanuel Kant in 1764 (Priest, 2004). The phenomenological movement can firstly be attributed to the German philosopher Edmund Husserl (1857-1938). His work was inspired by his tutor Franz Brentano and Husserl himself later went on to inspire his student Martin Heidegger (1889-1976).

The evolution of phenomenology as a methodology has derived from philosophy, and history uncovers several variations due to renewed interpretations and constant adaptations (Bondas, 2011). In the last decade, phenomenology has progressed into a mature research methodology particularly amongst nurse researchers and in the fields of education and psychology (Tuffour, 2017).

Phenomenology is well recognised as a research approach as well as a philosophic viewpoint (Dinkle, 2005; Dowling, 2007; Flood, 2010; Kafle, 2011; Miles et al., 2013) with its development influenced by epistemology

and ontology since its formation (Bondas, 2011). However, it is often viewed as an umbrella concept in research; therefore, it is necessary to be explicit about the basis that it is being used for (Bondas, 2011). The principles of phenomenology are relevant to nursing practice as it underpins Heidegger's belief "*What is it like to be in the world*". However, phenomenology does not offer awareness into caring and health, but it does provide a method to illuminate human existence into the field of caring (Dahlberg, 2006). The thinking behind the methodology and philosophical views of phenomenology link the concept of understanding phenomena to the human being's experience with a greater degree of consciousness (Qutoshi, 2018). Many phenomenological philosophers introduced their own nuances to the phenomenological philosophy (Bondas, 2011). Although several views and schools of thought exist, there still remains a commonly shared view that consciousness is central and understanding the subjective consciousness is vital (Qutoshi, 2018).

In addition to Husserl and Heidegger, many other philosophers contributed to phenomenology, including Jean-Paul Sartre, Merleau-Ponty, Hans Greg Gadamer, Paul Ricoeur and Max van Manen. As a result, many strands of phenomenology have surfaced, each one having their own particular focus (Brooks, 2015). This can prove confusing (Dowling, 2004) and a challenge for the novice researcher in addition to the complicated cryptic philosophical language (Miles et al., 2013).

The main phenomenological approaches are descriptive or eidetic influenced by Husserl, interpretive or existential referred to as Hermeneutics, driven by Heidegger and Gadamer and the Dutch (Utrecht) school of phenomenology; the latter being a combination of descriptive and interpretive influenced by van Manen's writings (Cohen and Omery, 1994; Connelly, 2010; Dowling and Cooney, 2012).

3.5.1 Descriptive Phenomenology

Descriptive phenomenology as suggested by the title centres on describing the experience of participants (Gelling, 2015), aiming to demonstrate the

essential structures in a way that is interpretative free (Bradbury-Jones, Sambrook S. and Irvine, 2009). Descriptive phenomenology is associated with Husserl's belief of epoche, accepting that phenomena have a key essence that can be objectively studied through 'bracketing' (Wilcke, 2002), an attempt to eliminate personal presumptions to ensure the researcher's previous beliefs do not influence the developing theory (Wilcke, 2002). Phenomenological reduction or epoché refers to the deliberate suspension of judgement (Priest, 2004). Another strategy employed to support transcendence is an imaginative variation which includes asking questions of the phenomenon to gain a deep understanding and exclude irrelevant data (Priest, 2004). The intuition of essences enhances the meaning of the experience (Qutoshi, 2018).

Husserl postulated that if a rigorous foundation for the natural and human science was to be developed then reduction was necessary (Paley, 1997), and that it was necessary to isolate particular essences from their experience to remain subjective (Brooks, 2015). Heidegger was not in favour of this approach recognising that our realities are decided by our senses (Scotland, 2012). Paley (1997) also criticises Husserl's view on reduction arguing that although the reductive technique may be suitable to reveal the essences of one particular experience it cannot clearly demonstrate the relevance to all experiences.

A phenomenological viewpoint relating to existence places focus on the conscious beliefs of objects rather than the natural attitude, which is transcended, enabled by reduction or bracketing, as a result, the phenomenon of interest is described and the true essence is revealed (Priest, 2004). Husserl believed entry to consciousness was through grasping phenomena, and this grasping was done intentionally (Lavery, 2003). Our knowledge is based on conscious awareness (Koch, 1995). Husserl's notion was that entry to the material world was through consciousness, and that knowledge was gained from experience (Lavery, 2003; Priest, 2004). Husserl was preoccupied with awareness and objects, and he used the term 'object' as a generic one which can refer to many things in the external

world, concepts essences dreams or data of consciousness (Paley, 1997). Husserl's intention was to study experience as it appears through consciousness without delay to avoid the phenomenon being blemished with several explanations as to its cause (Wilcke, 2002).

Lifeworld or 'Lebenswelt' was first voiced by Husserl and emerged as a result of his views on the natural attitude (Dahlberg Drew and Nystrom, 2001). Human existence and lifeworld are portrayed by intentionality (Dahlberg, 2006) and Husserl viewed intentionality as focusing the mind towards objects of study to develop knowledge of reality (Lavery, 2003). Merleau-Ponty built on the work of Husserl and Heidegger (Dowling, 2007), with his writings focusing on the four lifeworlds that are alleged to belong to the lifeworld structure. These four are utilised widely within the field of nursing research, namely, lived space (spatiality) Lived body (Corporeality) Lived time (temporality) and Lived human relation (relationality) (Dowling, 2007).

Frameworks have been proposed for descriptive phenomenological approaches, for instance, the 'Duquesne method' promoted by Giorgi and others (Giorgi, 2008, p. 34). Moreover, the Vancouver school, also grounded in descriptive phenomenology employs a seven-step process; silence, reflection, identification, selection, interpretation, construction and verification of meaning (Qutoshi, 2018).

3.5.2 Interpretive or Hermeneutic Phenomenology

Phenomenology and hermeneutics are often discussed interchangeably causing scepticism as both include separate schools of thought and methodology (Dowling, 2004). This can prove frustrating for the novice learner when undertaking research. Hermeneutic phenomenology is considered the second school of phenomenology (Dowling, 2004), and while this assumes elements of descriptive phenomenology, it then transforms and integrates them with the hermeneutic process of understanding (Wilcke, 2002). Moreover, whilst phenomenology may describe or interpret subjective accounts, the researcher can remain objective by acknowledging or bracketing beliefs during the process

(Pringle et al., 2011). Hermeneutics goes further than the description of concepts and essence to search for meanings embedded in life practice (Lopez and Willis, 2004). With hermeneutics, interpretation is an unending process that cannot be captured by a single vision (van Tonder, 2010).

Various schools of thought influencing developments in hermeneutics are from the writings of Heidegger and Gadamer; the latter advancing the work of Heidegger. Hermeneutic phenomenology is recognised as a research methodology with the primary goal to highlight the lived experience and uncover new meaning through interpretation (Dowling, 2004; Wilcki, 2002). Interpretive or hermeneutic phenomenology is a method of interpreting and describing human experience and is well placed as an appropriate methodology for human science research (Ortiz, 2009; Tan et al., 2009; Lavery, 2003; Tuohy et al., 2013).

Whitehead (2004) argued that hermeneutic phenomenology is a philosophy and not a methodology, suggesting the researcher whilst interpreting, withdraw the principles from the philosophy which relate to their study. However, perception can be selective, people perceive the same experiences in the same environment differently (Willig, 2013). Smith and Shinebourne (2012) remind us that "*Interpretation is always my own*". The hermeneutic enquiry concern is how individuals interpret the world given their historical, social, political and cultural background (Polit and Beck, 2006).

Research in the hermeneutic phenomenological tradition is based on the belief that study participants and researchers come to the investigation with fore-structures of understanding influenced by their individual backgrounds (Wojnar and Swanson, 2007). Fore-structures are beliefs held in advance of interpretation (Mackey, 2005). Finley, (2008) acknowledges that understanding is built on previous knowledge and therefore needs to be recognised. Benner, (1994) compares interpretive phenomenologists to cultural anthropologists, suggesting they need to be transparent about their own cultural background before visiting another person's and expect their culture to be challenged.

The focus of hermeneutic phenomenology is on an individual's subjective experience, revealing the world as experienced by the subjects through their life stories (Kafle, 2011), illuminating small details of experience in one's life otherwise taken for granted (Lavery, 2003). The hermeneutic approach recognises that human phenomena are loaded with meaning (Guignon, 2012) and provides the researcher with access to emerging meanings and rich data of the lived experience (Crowther et al., 2017). Hermeneutic phenomenology provides a glance at the meanings that reside within the human experience (Crowther et al, 2017). The hermeneutic process is viewed as a dialogical approach where the horizon of the interpreter and the thing being studied are merged (Dowling, 2004). The idea of the 'parts' and the 'whole' is a shared view within hermeneutics (Gullick Monaro and Stewart, 2017). This hermeneutic interpretive approach relates to Heidegger's ideologies of 'Being', and hermeneutics centres on existential-ontological of how individuals understand (Koch, 1999).

The popularity of interpretive phenomenology is evident in Psychology's development of interpretative phenomenological analysis (IPA), a method closely linked to hermeneutics and the writings of Heidegger. Its method of analysis has practical and simple guidelines and holds clarity and depth (Finley, 2008; Smith and Osbourn, 2008). IPA's references to 'double hermeneutics' describe the participant as making sense of the world and the researcher is attempting to make sense of their sense of the world (Smith and Osborn, 2008; Tuffour, 2017). This method of interpretation and reflection sits well with the hermeneutic circle that deals with the relationship between parts and the whole gaining a holistic interpretation of the experience (Tuffour, 2017).

3.6 Heidegger and Phenomenology

Heidegger's philosophy is an influential tool in phenomenological research (Horrigan-Kelly, Millar and Dowling, 2016), responsible for advancing phenomenology into interpretive or hermeneutic phenomenology. The focus of Heideggerian phenomenology is on ontology, the study of the meaning of being and offers a philosophical lens of an experience of being in the world (Gullick Monaro and Stewart, 2017). Husserl and Heidegger dominated the German phase of phenomenology (Dinkle, 2005), but Heidegger's writings were influential on the development of philosophy in France as well as Germany (Moran, 2000). Heidegger believed that humans have the ability to interpret their own experiences (Wilson, 2015) and acknowledged the main focus of philosophy was on the nature of existence, this being ontology (Dowling, 2004), believing that there are multiple views of reality constructed rather than one single reality (Lavery, 2003). Subject to this belief Heidegger was interested in exploring 'Dasein' or the lived experience; where the focus is on being in the world rather than in phenomena (Flood, 2010; Horrigan-Kelly, Millar and Dowling, 2016; Wilson, 2015). Heidegger's principal interests were essentially humanistic, placing the individual in the context of their life-worlds (Pascal, 2010). The main concepts in interpretive phenomenology focus on 'Dasein', life-world, existential themes, fore-structures and the hermeneutic circle (Tuohy et al., 2013).

3.6.1 Dasein

'Dasein' or being is a Heideggerian concept translated as 'human being' relates to how we make sense of the world and how we come to know of this place (Conroy, 2003).

This study sought to seek and understand Dasein, the meaning of Being, for individuals who are living in a world with an ICD. Heidegger's seminal text 'Being and Time' provides an analysis of the concept of Dasein, and how it relates to our everyday existence of 'Being in the world'. Moran (2000) describes Heidegger as one of the twentieth centuries great philosophers and refers to his work "*Being in Time*" without question as a philosophical

masterpiece. Dasein's basic mode of existence is Being-in-the-world-with-one-another (Pandiaraj, 2019). Through "*belongingness*" to the world, we experience things that are purposeful to us (Dahlberg, 2006). Dasein, when translated suggests '*The mode of being human*' or '*the situated meaning of a human in the world*' (Lavery, 2003 p. 24). A number of the ingredients that shape our being-in-the-world can be concealed and require interpretation in order to fully understand the true meaning (Wilcke, 2002). As Finlay, (2009) acknowledges, we experience a thing as something that has previously been interpreted.

An important aspect of being in the world is through our connectedness with others (Miles et al., 2013). As entities of the world, Heidegger, (2001/2008) asserted we alone do not contribute to our Dasein (our being-in-the-world), others also contribute to this process of living and we are unable to separate ourselves from this interaction (Horrigan-Kelly, Millar and Dowling, 2016; Peters, 2019). Dasein in its everyday concern lives as speaking with others (discussing, negotiating, struggling) based on its existential structure, which is always turned towards what is not already realised existential possibilities (Pandiaraj, 2019). Dasein understands itself closest in terms of its world, and the Dasein-with of others is viewed in terms of what is ready-to-hand within the world (Heidegger, 2001/2008). Heidegger, (2001/2008) referred also to "being in the world" "the ready to hand" within the world as a concern and interpreted as the phenomenon of care. Moreover, Heidegger, (2001/2008) recognised "care" (Sorge) as a basic state of Dasein, and argued that care is relational, with self (Miles et al., 2013). Concern is a character of being, involving being with or being towards other entities encountered in the world. In our dealings with concern, we encounter things that are unusual within what is ready-to-hand, and we find things that are missing, not at hand ["Zur Hand"] and not handy ["handlich"] at all (Heidegger, 2001/2008). Heidegger claimed that Dasein exists in the mode of authenticity and inauthenticity that offer Dasein many possibilities. Authenticity allows the choice to either win or lose oneself or never win oneself. Inauthenticity affords the choice to run away and forget that there is a choice available (Heidegger, 2001/2008). People can choose either to live

in an unauthentic or an authentic manner. An unauthentic individual adopts an unreflective view remaining trapped in their thoughts, whereas authentic individuals have a more attentive view of their mental life (Mortari, 2015).

3.6.2 Time

Heidegger appreciated the importance of the context of time, understanding it was not confined to the moment but associated with memories and feelings (Miles et al., 2013). He also emphasised that interpretation was grounded in time, acknowledging a person is temporally situated in-the-world (Mackey, 2005). How we interpret events that have occurred during specific periods in our lives influences our understanding (Tuohy et al., 2013). Heidegger recognised temporality as the foundation for our awareness related to our existence, allowing for past present and future experienced in unison (Mackey, 2005). Therefore, the researcher needs to position themselves and the participant's experience in the context of time to best develop understanding. This applies also in the context of space, not being in the actual space but the feelings and memories that emerge when in the space (Miles et al., 2013). Heidegger acknowledged that existence is not alone temporal but also spatial, the concept of space, related to the actual space in which the person finds themselves located at that time (Tuohy et al., 2013).

Husserl's philosophy of knowledge assumed one can separate knowing from being (Wilson, 2015). However, Heidegger dismissed this view of the human being/subject as a spectator of objects adopting that both subject and object were inseparable (Horrigan-Kelly, Millar and Dowling, 2016) and that knowledge cannot be dissected from life experiences (Wilson, 2015).

3.6.3 Fore Structures

Bracketing is one major distinction between Husserl's and Heidegger's philosophy. Interpretive phenomenology does not advise the researcher to bracket oneself from the research inquiry process, either in conversation, interview or when interpreting the text (Annells, 1999). Rather than bracket preconceptions, the researcher enhances awareness through the process of

reflexivity (Flood, 2010). Heidegger proclaimed that nothing is experienced without reference to an individual's background (Lavery, 2003). The interpreter inevitably brings certain background expectations and frames of meaning to bear in the act of understanding; these cannot be ignored, forgotten or bracketed (Koch, 1995).

Heidegger anticipated that fore-structure is closely connected with how one understands the world and understanding is linked with how a person interprets reality (Wojnar and Swanson, 2007). Bringing one's preconception into play means to interpret the text in a way that the text can speak, and every interpretation involves a relationship with others due to the verbal nature of interpretation (Gadamer, Weinsheimer and Marshall, 2004). A person's previous experience may influence how they deal with similar situations in the future and can either have a positive or negative effect on an individual. Heidegger's philosophy recognises that we are born into an already existing world, and that world is shaped and moulded by our cultural heritage. Interpretation and understanding of everyday events occur as a result of this background knowledge and determines how we and make sense of these situations when they present. Heidegger is always seeking the thoughts behind our thinking (Moran, 2000).

3.7 The Hermeneutic Cycle

Heidegger employs the hermeneutic circle method of analysis which entails continuously revising, moving between the parts and the whole of the text acknowledging that the researcher is always part of the meaning in the text (Reiners, 2012). The hermeneutic circle is a metaphor adopted from Heidegger which describes the circular movement from the parts to the whole in order to understand the experience differently (Koch, 1996). Heidegger, (1962) referred to this process as entering into a hermeneutic circle of understanding that reveals a blending of meanings as expressed by the researcher and the participants co-constitutionality (Koch, 1995). The hermeneutic circle understands the whole in association with the parts of an individual text and understands the parts through understanding the whole (Mason and May, 2019). The hermeneutic cycle moves forward and

backwards, are never-ending, and through this thorough interaction, the phenomenon is unveiled (Charalambous, Papadopoulos and Beadsmoore, 2008). Subject to this, human understanding evolves through recognising mutually dependent relationships in association with the context that they are found (Mason and May, 2019).

3.8 Gadamer

Hans-Georg Gadamer was a German philosopher, born February 11th, 1900, who built on Heidegger's and Husserl's beliefs and developed his own approach to understanding (Wilcke, 2002). Like Heidegger, Gadamer focused on the importance of common language and common background of meaning recognised as part of the hermeneutic circle (Ortiz, 2009), and he advanced hermeneutics from seeking an appropriate method of understanding text to an enhanced ontology of understanding inclusive of history and language (Mason and May, 2019).

Gadamer acknowledged the importance of language in forming experience and understanding (Wilcke, 2002). Interpretation for Gadamer was a means of re-experiencing the world through thought and language, resulting in understanding and illumination of personal horizons (Mason and May, 2019). He believed that we stand in tradition and that tradition is connected to language (Tan, Wilson and Olver, 2009). This can be achieved by focusing on words whilst writing the text, exploring the origins to illuminate the researcher's understanding (Wilcke, 2002). Gadamer aimed to reveal the nature of human understanding, arguing that understanding is not alone confined to acts of consciousness but a constant characteristic of our history and tradition (Mason and May, 2019). Recognising that interpretation is a mutual process, the relationship between researcher and participant, or text and reader is a recurrent discourse (Gadamer, Weinsheimer and Marshall, 2004; Tan, Wilson and Olver, 2009).

In his writings, Gadamer refers to the hermeneutic circle as the fusing of horizons that are circular in action (Dowling, 2004). The fusion of horizons occurs through dialogue designed to understand what people speak about

(Wilcke, 2002). Gadamer recognised that the horizon concerning the present cannot be formed without the past (Mason and May, 2019). A person's actual Horizon is never set; it just progresses as their scope of vision expands (Wilcke, 2002).

Gadamer's contribution to hermeneutics furnishes it with a theory to understand humans (Charalambous, Papadopoulos and Beadsmoore, 2008), and this has been further advanced by Ricoeur, with both holding similar beliefs on the importance of understanding text. Their theories have guided this study and assisted the researcher to develop a deeper understanding of participants' experience of living with an ICD.

The following section addresses the work of Ricoeur and his contribution to the field of philosophy. In this study, consideration was given to the importance of congruence between the methodology and the research methods. Ricoeur's interpretive analytical framework sits comfortably with Heidegger's interpretive philosophy as they both held similar worldviews. Ricoeur's framework of analysis is central to this study. Further details on the stages of interpretation are discussed in detail and illustrated with examples in Chapter Five.

3.9 Ricoeur

Paul Ricoeur was a French philosopher, born 27th February 1913 renowned for his theory of interpretation. Inspired by the work of Heidegger and Gadamer, Ricoeur's contribution to this group was acquired from Gadamer's understanding of ontology and his methodological judgments (Charalambous, Papadopoulos and Beadsmoore, 2008). Ricoeur's work influenced the development of Vancouver's school of phenomenology (Halldorsdottir, 2000). Ricoeur is best renowned for his theory of interpretation which recognises the connection between the presumptions made from the interpretation of what is already known by the interpreter (Ghasemi et al., 2011).

Ricoeur connected the epistemological processes of interpretation with the ontological view of the interpreter throughout the research process (Geanellos, 2000; Horrigan-Kelly, Millar and Dowling, 2016). He described the theory of interpreting the text as the hermeneutic arc, which refers to the back and forth movement among an in-depth and naïve interpretation (Tan, Wilson and Olver, 2009), and perceived that understanding was achieved through interpretation, therefore deemed a suitable choice to reveal the phenomenon within this study. Ricoeur's theory of interpretation recognises that interrelationship between the notions formed from the interpretation and that which is understood by the interpreter (Tan, Wilson and Olver, 2009), and proposes that interpretation is mastered through explanation and understanding working in unison through the dialectic of distance to form the horizons of understanding in our lives (Mason and May, 2019).

Ricoeur concurred with Gadamer's theory that language shapes the basis of thought and interpretation (Mason and May, 2019). Utilizing this method assists the researcher to understand the meaning of participants' experience by interpreting the interviews transcribed as a text (Dreyer, Steffensen and Pedersen, 2010). Ricoeur's theory of interpretation portrays a broad understanding of the lived experience, consisting of several stages of interpretation: a naïve reading, structural analysis and critical analysis and discussion (Dreyer, Steffensen and Pedersen, 2010).

Ricoeur's theory of interpretation enables the researcher to develop a deeper understanding of "being in the world" (Dreyer and Pederson, 2009), using distanciation, appropriation, explanation, understanding, and interpretation (Tan, Wilson and Olver, 2009).

3.9.1 Distanciation

Distanciation is the process of estrangement and appropriation is the "remedy" that could "rescue" cultural beliefs of the past from the alienation of distance (Ricoeur, 1976). Ricoeur refers to distanciation as being objective or standing separate from the text (Tan, Wilson and Olver, 2009). Ricoeur (1976) believed that to explain a text meant to view it as an

expression of socio-cultural need, responding to certain perplexities positioned in time and space. This involves viewing the text as a co-shared discussion (Horrigan-Kelly, Millar and Dowling, 2016) or a method to establish or create a mental or emotional distance.

The concept of distanciation is created through the relationship between spoken language and text (Mason and May, 2019; Petrovici, 2013). Ricoeur argues that the text is more than communication between humans, it is a paradigm of the distanciation of communication, arranging the concepts into four themes (Dreyer and Pederson, 2009; Tan, Wilson and Olver, 2009).

Speech and written language are both forms of discourse (Mason and May, 2019). Ricoeur distinguished between discourse and written text, setting out text as speech now written, as structured work, and presented as the speaker's world, negotiating between the written text and self-understanding (Horrigan-Kelly, Millar and Dowling, 2016; Tan, Wilson and Olver, 2009). Ricoeur (1976) refers to discourse as an event that links two events, the act of speaking and hearing. Discourse with texts or other people; help create an awareness of aspects of our preunderstanding related to history and culture and phenomena that we take for granted (Lindseth and Norberg, 2004). Ricoeur recognised discourse was associated with a specific time period (Horrigan-Kelly, Millar and Dowling, 2016). Discourse lives in the moment of the speech event, spoken language is not fixed, it is the spirit to a passing event, in contrast, written language is fixed, and through writing the intended meaning of the speech event occurs (Mason and May, 2019).

3.9.2 Appropriation

Appropriation is the concept for the actualisation of meaning as spoken to somebody (Ricoeur, 1976). Appropriation is closely associated with what Gadamer refers to as the fusion of horizons; the world horizon of the reader becomes fused with the world horizon of the writer (Ricoeur, 1976). Appropriation never occurs through direct capture, understanding is made possible not only by attempting to understand but by revealing ourselves to the text and gaining new ideas in return (Bühler, 2011). In other words, our

access to understanding occurs through past experience, cultural beliefs and previous knowledge relating to a situation.

3.9.3 Understanding and Interpretation

The process undertaken in analysing and interpreting the data using Ricoeur's theory of interpretation can be viewed as an analytical framework (Ricoeur., 1973, 1975, 1981, 1991). Interpretation is the manner of disclosing new forms of being (Ricoeur, 1975), and is informed by knowledge (Tan, Wilson and Olver, 2009). The relationship between explanation and understanding involves the movement back and forth between the texts. Ricoeur (1971, 1981) refers to the term 'hermeneutic arc', as the movement back and forth in circles from naïve understanding to developing an in-depth interpretation (Tan, Wilson and Olver, 2009). Interpretation focuses on what the text talks about and what the text says (Dreyer, Steffensen and Pedersen, 2010).

Ricoeur concentrated on textual interpretation in order to broaden his theory focusing on reflection, language and moving vernacularly between explanation and comprehension (Dreyer and Pederson, 2009). This interpretation places a new perspective on things which enables the researcher to visualise the world independently (Charalambous, Papadopoulos and Beadsmoore, 2008). To make one's own that what was previously "foreign" remains the aim of hermeneutics (Ricoeur, 1976).

Ricoeur also recognised subjective knowledge which displayed the researcher's and participants' interpretations (Horrigan-Kelly, Millar and Dowling, 2016), and his philosophical method endeavoured to bridge the gap between ontological and critical hermeneutics, which prior to this was believed to be incompatible (Charalambous, Papadopoulos and Beadsmoore, 2008). Ricoeur concentrated on textual interpretation as the main aim of hermeneutics and developed a theory of interpretation considering reflection and language (Ghasemi et al., 2011). Ricoeur believed that the past can be remembered in the present, that the present can influence positive belief in the future (van Tonder, 2010), and

acknowledged the mutual resemblance between phenomenology and Hermeneutics (Tan, Wilson and Olver, 2009).

Ricoeur's theory of interpretation consists of several stages of interpretation: a naïve reading, naïve understanding and in-depth understanding. The process involved in the analysis is outlined below.

3.9.4 Phase 1: Naïve Reading or Explanation

Naïve reading is referred to as the first reading of all the interview text (Dreyer, Steffensen and Pedersen, 2010). Ricoeur recommends reading and re-reading the text utilising an iterative process of moving backwards and forwards between explanation and interpretation. At this point, Ricoeur recommends the practice of distanciation (Ricoeur, 1976).

In keeping with all approaches to analysis in phenomenology, the text is read to gain a general sense of the interview text as a whole to achieve an instant understanding of the meaning of the phenomenon (Dreyer, Steffensen and Pedersen, 2010). During this process, the transcripts and researcher's journal notes are examined, analysed and coded (Tan, Wilson and Olver, 2009).

3.9.5 Phase 2: Analysis: Naïve Understanding

This method of analysis entails exploring if what has been coded in level one is closely connected. This stage is referred to by Ricoeur as the understanding process which connects the world of the author with the world of the reader (Ghasemi et al., 2011). Common meanings are sorted into themes and usually supported with quotations (Coolican, 2104). The use of quotes reflects the epic view of the person experiencing the phenomenon of cultural beliefs and values (Lo Bionda-wood and Haber, 2006). Data is further coded into subthemes that are related to history, family, culture, communication and relationships (Tan, Wilson and Olver 2009).

3.9.6 Phase 3: Analysis: In-depth Understanding

The stage of the analysis involves the interpretation of the text as a whole. The approach of reaching an understanding entails moving back and forward from explanation and understanding (the hermeneutic arc). As the process continues, interpretation moves from immature understanding to a more in-depth understanding (Ghasemi et al., 2011). Interpretation is finalised as appropriation when reading reveals something like an event of discourse, an event in the present moment, “*as appropriation, interpretation becomes an event*” (Ricoeur, 1976, P 92). In other words, our access to understanding occurs through past experience, cultural beliefs and previous knowledge relating to a situation.

3.10 Rationale for the Choice of Methodology

It was never the intention of Husserl or Heidegger to develop a research methodology, their interest was in the field of philosophy (Miles et al., 2013). Nevertheless, many research groups have adopted their philosophies as methods to guide their research. The approach and design of any research study should be those that are most appropriate to the questions being raised (Taylor and Thomas-Gregory, 2015).

Although Husserl’s descriptive approach may have been suitable, I was drawn more to interpreting participants’ meaning rather than providing a description of the phenomenon’s central meaning structure. Moreover, I was approaching the study with many preconceptions which would have been difficult to bracket and set aside. Subject to this, understanding is linked to interpretation rather than the description (Bradbury-Jones, Sambrook and Irvine, 2009). In keeping with the interpretive paradigm, the researcher undertook several periods of reflection throughout this study.

3.11 Reflection

Whilst the choice of methodology and methods should acknowledge the research aims of the study, it is also important that it reflects the researcher’s academic and personal stance.

Phenomenology encourages exploring one's own thoughts and ideas about a subject. In completing this study, I found it necessary to examine my own pre-understandings as it is important to recognise what influences my interpretation. My choice of the research question was influenced by my professional history as a nurse with an extensive background in cardiology. In addition to this, I have experience in psychiatry which contributed to my knowledge and understanding of how life-threatening illnesses can impact on one's mental health. Throughout my career, I have experienced many individuals who physically recovered from illnesses however mentally found it extremely difficult to accept and adjust. This awareness led me to become inquisitive and interested to explore further what the experience was like for this cohort of people who had to continue living their everyday life having had an implantable defibrillator inserted. Although I had background clinical knowledge it was limited concerning individuals' day to day personal existence. I also had an uncle whom I was extremely fond of dying suddenly from a cardiac condition when I was only ten. Reflection during my research reminded me of the event causing me to question if this perhaps influenced my choice of career and research topic. However, I do believe my personal interest in pursuing this study evolved as a result of an encounter with a young man who has an ICD. I changed roles some years ago to the post of Night Manager during this time I encountered this young man who was attending the emergency department and had an ICD implanted two years previous and was still afraid to leave his house. This concerned me greatly; I recognised that these patients' needs were neglected despite been reviewed at clinic appointments by health care personnel, highlighting a need for greater support. I was aware of having worked in the cardiac rehabilitation department for many years that patients with ICDs were rarely referred to services. Although services have advanced considerably with the introduction of new technology and lifesaving devices, there still appears to be limited psychological support to assist these people to cope with the

aftermath of a significant life change. I was also keen to explore if and how the Irish healthcare system supported their recovery throughout this experience. Based on the study's aims and objectives, I felt that a qualitative approach was the appropriate method to use to address this. I believed that phenomenology as a methodology would best assist me as a researcher to explore deeper as this approach best captures the participants' lived experience. This would assist me as a researcher to develop a greater understanding. I felt because of my extensive cardiology background it would be difficult to set aside all of my previous knowledge, therefore, I chose Heidegger's philosophy to guide my choice as he rejected Husserl's notion of bracketing one's knowledge.

3.12 Conclusion

This chapter describes the methodological features of the study and a rationale for this choice. An interpretive paradigm that employed hermeneutic phenomenology was discussed.

The focus of the study was to illuminate the meanings participants ascribed to their experience; therefore, this method was deemed the most appropriate methodology to accomplish the aims of this study.

The method in which the philosophical viewpoint has shaped the research, the method of data collection and analysis, will be addressed in the following chapter. In common with other qualitative methodologies, this method involves purposive sampling and interviewing, allowing the data to be collected from those experiencing the phenomenon.

Chapter Four: Research Methods

4.1 Introduction

This chapter outlines the study's ethical issues, sampling strategy, data collection, rigour and analysis.

4.2 Ethical Issues

Ethical implications must be considered when undertaking research that includes human participants (Gelling, 2016). The researcher should always be aware of the impact that research may have on study participants, while simultaneously being ethically sensitive and morally competent (Beauchamp & Childress, 2013; Houghton, Casey and Murphy, 2010).

Ethical approval was granted in August 2017 from the researcher's university research ethics committee and three hospital research ethics committees between 30th August 2017 and 23rd January 2018 (see appendix: 3).

To ensure that the study was conducted in an ethically correct manner, key ethical issues were addressed including the four principles of autonomy, non-maleficence, beneficence and justice which are important in the area of medical ethics (Beauchamp and Childress, 2013: Beauchamp and Childress, 2001, p.13). In addition, the principles of Good Clinical Practice (GCP), the Helsinki-ethical principles and HSE data protection guidelines were adhered to throughout (Berghammer, 2014; HSE, 2018; Kong and West, 2013; Verna, 2013; WHO, 2005; WHO, 2008). The GCP is the international ethical, scientific and practical standard to which all clinical research is conducted. Compliance with GCP provides public assurance that the rights, safety and wellbeing of research participants are protected, and that research data are reliable (GCP) (Berghammer, 2014).

Potential participants were invited to participate and given an information pack informing them of the study. They were given between two weeks to

decide if they wished to be included. Participants were also assured of their rights to withdraw from the study without consequence at any stage (see appendix: 4).

Written consent was obtained before interviewing and participants were once again made aware of their right to refuse to continue at any time without consequence. The data protection measures were described in all consent forms (See appendix: 4).

The researcher was conscious that recalling experiences could potentially be emotive for participants. From this perspective, a distress protocol was developed and adhered to acknowledging the key principle of non-maleficence (see appendix: 5).

In order to ensure those participants' confidentiality and anonymity was maintained throughout the study, the following steps were implemented. The participant was assured of their confidentiality and anonymity being preserved via data coding and removal of all identifiers from all written material. All transcripts and audiotapes employed in this study have been stored in accordance with NUI Galway's REC data storage policy. The interviews which were not transcribed by the principal researcher were contracted out to a professional transcriptionist who signed a declaration of confidentiality (see appendix: 6). The transcriptionist received tapes labelled only with coded pseudonyms. Each participant was given a coded pseudonym which was used on all written materials. Participants' true names and contact details were stored separately on an encrypted file, and each participant was allocated a pseudonym. A key connecting the pseudonyms with only the code numbers of the true identity data was kept in an encrypted password-protected file which is accessible only by the researcher in accordance with the NUIG guidelines.

4.3 Sampling Strategy

The study's aim was to explore the experiences of adults living with an ICD to develop a deeper understanding of this phenomenon; therefore, a

purposive sample was deemed the most appropriate sampling approach. Purposive sampling refers to individuals being chosen with a 'purpose' to represent those knowledgeable about the experience of interest based on a selected criterion (Connelly, 2010; Parahoo, 2006; Richie and Lewis, 2003). This is also known as judgment sampling which involves the researcher purposefully choosing individuals that meet the inclusion criteria (Crookes and Davis, 2004). Purposeful sampling is utilised extensively in qualitative research to discover and select information-rich cases related to the phenomenon of interest (Palinkas et al., 2015). The selection choice is representative of those individuals within the research that have experienced the phenomenon (Coolican, 2014).

4.3.1 Sample Size

Different principles concerning sample size apply to qualitative research in contrast to quantitative studies; therefore, it is important to provide a clear methodological rationale for the chosen sample size (Crookes and Davis, 2004). Small and purposeful samples are used in phenomenology as it facilitates the identification and selection of information-rich cases related to the phenomenon of interest (Connelly, 2010; Palinkas et al., 2015). The sample size required within interpretive phenomenology is determined by the achievement of data saturation (Hennink et al., 2017; Polgar & Thomas, 2008). Fusch and Ness (2015) postulate that no one size fits all, more is not essentially better than less. Morse (2015) argues that as we saturate characteristics within categories that appear as important, as our understanding grows, phenomena become stronger, more evident and certainty prevails. However, it can be argued with a hermeneutic approach that saturation may never be achieved due to the uniqueness of the individual's experience. Moreover, Hennink et al. (2017) emphasise that assessing saturation is more complicated than it seems at the outset. Data saturation is a neglected field as the concept is hard to define, what is adequate for one study is not nearly enough for another (Fusch & Ness 2015). Nevertheless, saturation remains an important component of rigour (Morse, 2015).

4.3.2 Inclusion Criteria

Inclusion in the study was based on the following criteria:

- Male and female participants
- Aged over 18 years
- Participants must have had the ICD device in-situ for a period of over 1 month to a maximum of 10 years
- Ability to read and speak English

Consideration was given to limiting the sample of younger or older recipients as their needs can be quite different. However, the inclusion of younger individuals solely would have resulted in an extremely small sample. It was important that participants had the experience of the device in situ for a period of time so that they could relate to how it was affecting their lives. It was considered that having a device for less than one month was not sufficient time and 10 years was adequate time to give an account of how the passage of time changed their experience of living with the device.

Because of lack of funding for the study, interpreters and translators were not a viable option, therefore it was important that participants were able to read and speak English in order to fully understand what the study involved and give their consent and converse with the interviewer.

Individuals whose ICD had activated and those who had not received a shock from their device were included in the sample. Individuals with mental health issues were included in the sample.

I was invited to present my research at one of the hospital's research ethics committees. During the meeting, a question was raised by a member of the committee concerning the need for the identified upper age limit. Following discussion with the wider supervisory team, it was agreed, that application would be made to the respective research committees to include an amendment to adjust the age to include all individuals 18 years and over. Participants needed to have the experience of having the device in situ for a

period so that they could relate to how it was affecting their lives. It was considered that having a device for less than one month was not enough time to give a realistic account of their experience, and 10 years was adequate time to give an account of living with the device. Because of lack of funding for the study, interpreters and translators were not a viable option, therefore participants needed to be able to read and speak English to fully understand what the study involved and give their consent and converse with the interviewer.

4.4 Recruitment

Three acute hospitals within the Republic of Ireland were chosen as the research settings. All acute hospitals offer an ICD service. The researcher was interested in capturing the perspective of representatives from both rural and urban locations, these sites were therefore purposely chosen. All individuals that had experienced the phenomenon and satisfied the inclusion criteria in the included sites were invited to participate.

Following ethical approval, an identified gatekeeper at each site was contacted by phone and followed up by email and forwarded the information packs which included an information letter, expression of interest letter and consent form (see appendix: 4). An email was also sent to the cardiologist in the chosen sites outlining study details and objectives (see appendix: 7).

The chief cardiac technician in two of the hospitals and a clinical nurse specialist in one hospital were the identified gatekeepers. Gatekeeping involves a process where researchers gain access to the research setting under study and to the potential participants (Kawulich, 2011). Gaining official access and cooperation from research sites and participants can differ depending on the study (Wanat, 2008). The gatekeepers also agreed to display a poster (see appendix; 10) in the cardiology department. If any participant was interested in the study they were asked to complete the expression of interest form and return it to the gatekeeper. The gatekeeper, in turn, notified the researcher, who followed up with the interested person.

A purposive sample of 27 participants, 13 males and 14 females were recruited for this study. They ranged in age from 22 to 78 years. The aim was to purposely select participants who had experienced the phenomenon being explored based on the inclusion and exclusion criteria. Participants had their ICDs inserted for both primary and secondary prevention and had their devices implanted between one and ten years. A brief description of the participants' demographic profile is outlined in section 4.7 and table 4.2.

Table 4.4.1 below provides a breakdown of the gender and number of participants that participated in the study.

Table 4.1 Recruitment by Geographical Sites

Area	Gender/Female	Gender/Male	Number
Site 1	9	9	18
Site 2	2	2	4
Site 3	3	2	5
Total	14	13	27

The researcher was mindful that should data saturation not be achieved; additional participants would be recruited. It became evident following the first ten interviews that similar stories with similar meanings were emerging and data saturation was achieved. However, the researcher continued to interview and recognised that similarities were apparent amongst participants of similar ages, and no new data was emerging. Evidence of data saturation is illustrated in chapter 5.

4.5 Qualitative Interviewing

There are many types of qualitative inquiry and methods of qualitative data collection that are associated with the humanistic tradition (Jackson, 2007). The most common means of acquiring information in qualitative studies is by interview (Cleary, Horsfall and Hayter, 2014; Mitchell, 2015; Ryan, Coughlan and Cronin, 2009; Taylor and de Vocht, 2011), from those who

have experienced the phenomenon (Connelly, 2010). The uniqueness of interviews is that rich data is produced relating to the individual's personal experience (Gelling, 2015).

The three main types used in qualitative research are focus groups, individual semi-structured and unstructured interviews. Information on a variety of situations can be uncovered by interviews (Mitchell, 2015). Semi-structured interviews are flexible; interviewers can begin with a questioning plan but move to a more conversational style of an interview (O'Leary, 2004). Unstructured interviews attempt to draw out beliefs, information, options, and themes without predefined questions (O'Leary, 2004) and are used to explore phenomena (Parahoo, 2006). Focus group interviews allow sharing and discussing experiences relevant to the research phenomena being explored (Gelling, 2015). However, not all participants feel comfortable conversing in an open group forum. Focus groups may not function for all, as group dynamics might suggest some participants feel too uncomfortable to offer honest views with others present (Gelling, 2015).

An unstructured individual interviewing technique was utilized for this study and one that is frequently used when undertaking hermeneutic phenomenology. Unstructured interviews enable participants to speak freely (Dempsey et al., 2016; Taylor and deVocht, 2011) and do not employ a specific structure for questioning (Ryan, Coughlan and Cronin, 2009). It is recommended that interviews are conducted in a quiet private, relaxed and comfortable environment that is convenient to the participant. It is important that the interviewee feels comfortable and relaxed; therefore, the selection of a suitable location for data collection is important and may affect the study being explored (Crookes and Davis, 2004).

One to one interviews involve face to face conversations (Ryan, Coughlan and Cronin, 2009), this method of interviewing presents as an opportunity to observe the participant's body language, facial expression and probe further. The researcher must be aware of nonverbal cues such as facial expressions and prolonged silences. Building up a trusting relationship with participants

is of utmost importance so that the conversation appears comfortable and flows. By employing this technique participants have the opportunity to narrate their experience allowing the researcher to grasp its true meaning. The researcher must probe into the participant's world in order to develop a shared understanding of how their existence in this social world is influenced by the phenomenon being studied (Birks Chapman and Francis, 2008). Nondirective probes change the focus of the conversation in a natural way, extracting more detailed information from the participant (Dempsey et al., 2016). The importance of active listening is highlighted in the literature to keep a focus on what is being said about the topic. Active listening during the interview process is vital as it leads to probes, which assist to clarify what the participant has said and also provides the opportunity to stimulate new thoughts obtained through dialogue (Lo Bionda-Wood and Haber, 2006). Dilley (2000) acknowledges listening skills as one of the most central elements of qualitative data collection and the most difficult to learn. Effective interviewing entails good interpersonal skills and qualities (Mitchell, 2016). The researcher's position is not a counsellor therapist but an observer, a listener, and a learner (Rossetta, 2014).

It is impossible to predict in advance what will be revealed in conversation (Gadamer, 1999) and prove challenging when dealing with vulnerable populations (Ryan, Coughlan and Cronin, 2009). Therefore, receiving private and personal information during a qualitative interview can determine a good interview for the researcher and may be a cathartic event for the respondent (Scerri et al., 2012). In addition, the researcher must be cognisant of inviting participants to engage in this reflective process and consider the consequences of asking them to revisit unpleasant experiences (Birch and Miller, 2000). The topic may be viewed as sensitive, or the research may arouse emotions, and participants should be afforded access to appropriate supports (Dempsey et al., 2016; Walker, 2007). Therefore, it is important that the researcher recognises any potential issues that the study may unearth (Sanjarie et al., 2014). Interviews are not necessarily therapeutic (Rossetto, 2014). Bell (2014) claims that a key advantage of interviewing is its adaptability, however, it can be time-consuming.

However, Parahoo (2006) argues that completely unstructured interviews can be problematic to manage. Balls (2009) argue that although nurses proclaim to be good listeners, they rarely explore people's experiences. Therefore, this highlights the importance of a pilot interview.

Interpretive researchers reflect critically on their biases or pre-understandings so as not to impede their questions (Benner, 1994). However, there can be potential for bias with interviews depending on how the interview is conducted (Crookes and Davis, 2004; Ryan, Coughlan and Cronin, 2009). Our pre-understandings and bias can be challenged and changed, subject to our ability to listen (Benner, 1994). Some authors support the use of a reflective diary viewing it as a helpful aid to reflect on interview skills and beneficial in creating awareness of reflexivity (Baille, 2015; Balls, 2009; Clarke, 2009; Engin, 2011; Nadin and Cassell, 2006). Applying principles of reflexivity may support the researcher to develop a deeper awareness of the participant's journey and allow their story to unfold. Such self-reflection permits the researcher to track ideas, understand their own thinking and create further insights (Cleary Horsfall and Hayter, 2014). Cypress (2017) acknowledges that a limitation of phenomenological studies is the researcher being the only instrument conducting the data collection and analysis which can affect reliability. Validity can also be a challenge in qualitative research when undertaking unstructured interviews as a method of data collection, but continual verification and careful recording can address this (Cypress, 2017).

Several researchers choose to conduct a pilot interview prior to conducting the actual study interviews. Pilot interviewing provides an opportunity to choose the appropriate venue, and improve interview skills (Janghorban et al., 2014). It can also be used as a method of testing the data analysis format. Usually, there are no major changes applied to qualitative study design following a pilot interview, therefore many studies include some or the entire pilot in the main study (Ismail, Kinchin, and Edwards, 2018).

The researcher conducted one pilot interview and this interview was included in the main study.

4.6 Pilot Interview

Once ethical approval was received a decision was taken to undertake a pilot interview before beginning the study. The pilot interview was conducted in December 2017, to test the technical equipment, evaluate the researcher's interview skills and review the interview schedule if necessary. The interview guide was developed based on unstructured interview guidelines in keeping with hermeneutic phenomenology (see appendix: 8). The pilot interview was conducted with an individual attending the cardiology clinic who agreed to participate and met the inclusion criteria. Contact was made, an information pack was provided, and a suitable date and location of the participant's choice were arranged (see appendix: 4). Prior to commencing the recorded interview an explanation of the interview format was provided by the researcher and written consent was obtained (see appendix: 4d). The participant was advised that this was a pilot interview and may or may not be included in the main study. The participant agreed to the interview being audio-recorded and was informed that the researcher would only ask one question "Tell me about your experience living with an ICD". The participant was advised that throughout the conversation, the researcher may occasionally question particular points to expand on areas that required further clarification. An assurance was provided that all discussions would remain confidential. The participant was also advised that anonymity would be maintained during the transcription and presentation of findings. The interview took approximately thirty minutes, was transcribed verbatim and analysed following the steps of Ricoeur's theory of interpretation (Ricoeur, 1976). Following a review of the transcript with the researcher's supervisors, it was agreed that the interview included rich data with no adaptations made to the research design it was agreed to include in the main study and the participant was informed.

Including the pilot interview in a study's main findings is undertaken when the data is rich (Glasz, 2001). A reflective account of the interview was also

undertaken. Such self-reflection permits the researcher to track ideas, understand their own thinking and create further insights (Cleary, Horsfall and Hayter, 2014). The pilot interview was helpful for many reasons; firstly, it allowed an opportunity to reflect on interview skills and the overall interview format, secondly, it provided an opportunity to trial the equipment, and finally, it was an opportunity to reflect on what went well and areas for improvement (as outlined in the reflection below).

4.6.1 Reflection

I had checked my equipment several times as my recorder was new, and I wanted to ensure that I was comfortable using it. The interview took place in a quiet room. The room was comfortable and relaxed and noise-free.

I felt comfortable and she appeared by her smile and body language was relaxed and comfortable. I felt I conveyed respect towards the interviewee by clarifying prior to the interview if she was happy to participate in the interview and we could reschedule if she wished. She was confident that she wished to continue and verbalised this. She had no objections to the interview being recorded and was happy to talk about her experience; this, in turn, led me to feel relaxed. She was a good historian, this I found helpful; she never deviated from the subject. She was very much matter of fact. This is what happened, this is how I dealt with it, and this is where I am now. That's all I have to say about it. This I found helpful, I found her easy to listen to. Although on occasions because of her accent I had to listen extra carefully to ensure I picked up exactly what she was saying. I feel I entered the interview with some preconceived ideas, due to my background experience, I feel I did try to suppress these views during the interview and wear my researcher's hat. But on reflection, I think some of her experiences surprised me as I would have had my own preconceived ideas as to how an ICD may impact on a person's life, and the areas that affected her most seemed to be "not being in control".

I was feeling slightly anxious but comfortable, more comfortable than I had expected to feel. I was thinking I hope she understands that I cannot speak here; I am only going to clarify points that require further clarification. But I felt by her body language and her non-verbal's she wanted to say something, and I discussed this following the interview. I felt by her that she had allocated herself a certain amount of time to do the interview and she was happy to finish.

I clarified the purpose of the interview well at the beginning but perhaps not the format. I felt throughout the interview I listened attentively and maintained good eye contact. I occasionally used vocal prompts i.e. "Yes Yes" and nodding my head to display my full attention and encourage the interview to continue speaking. However, as I had never undertaken an unstructured interview before I was unsure how much or how little to respond and if she expected me to interrupt or converse. I on occasions felt that perhaps she expected me to speak or respond. I could have been more specific before the interview although I explained the process. On reflection and from discussion with my supervisors it would have been helpful if I had informed her at the beginning that I would not interrupt only to take her back to clarify a point. I had explained the process at the beginning but going forward I would explain this in greater detail before putting on the tape. Also on reflection, I was unsure if I clarified enough or if I lost opportunities to probe. The ability to investigate further by probing deeper may have helped clarify some pertinent points during the interview process.

I felt the interview ended abruptly, on reflection I could have summarised more effectively. I also feel I could have started it better. I did not have a pre-rehearsed plan which I will consider for future interviews. I felt I could have concluded better. I feel I did summarise but perhaps not as effectively as I could have. I could have been more specific before the interview about only interrupting

to clarify. There were occasions that I felt the participant was waiting for me to ask a question. I was aware that while the interviewee was talking, I was listening attentively to her experience, focusing on aspects which later I would like to get greater clarification.

I feel have learned from this experience, I believe that I did demonstrate some positive qualities during the interview but there are aspects and skills that I need to improve upon which I have mentioned earlier. Having undertaken this reflection of the pilot interview some areas which require improvement is highlighted. While the interviewee was talking, I was listening attentively to her experience, focusing on aspects which later I would like to get greater clarification. This interview led me to appreciate the need to carefully plan future interviews and allocate sufficient time especially if it involves long journeys for the researcher as it is impossible to anticipate travel during winter weather.

On reflection, I was conscious of what the participant was saying in the context of the study. Is she answering the question? As a result, I learned that is important to provide a clear explanation of what an unstructured interview involves before commencing the interview.

4.7 Who are the Participants?

The participants were both male (n=13; 48%) and female (n=14; 52%). Participants were aged between 22 and 78 years. ICDs were implanted between 6 months and 10 years. Participants (n=63%) had a history of a previous cardiac arrest. The participants had their ICD implanted for the following reasons, long QT syndrome, arrhythmia, dilated cardiomyopathy, heart failure and genetic conditions. Participants were living between 10 and 70 km from the nearest hospital. The following table (4.2) provides an outline of the participant's characteristics.

Table 4.2 Study Participants' Characteristics (n=27)

Characteristic	n (%)	Characteristic	n (%)
Age Group		Driver	Yes 24 (88%) NO 3 (11%)
18-25	2 (7.4%)		
26-35	4 (14.8%)		
36-45	7 (25%)		
46-55	2 (7.4%)	Distance from hospital (Kilometres)	
56+	12(44%)	0-10	13 (48%)
Gender		11-20	5 (18%)
Male	13 (48%)	21-30	4 (15%)
Female	14 (52%)	31-40	2 (7.4%)
Previous history of cardiac arrest	Yes 10 (37%) NO 17 (63%)	41-50	2 (7.4%)
Length of time ICD in situ		50+	5 (18%)
0-2 years	10 (37%)	Employment	
2.1 years-4years	4 (15%)	In employment	15 (55%)
4.1 years to 6 years	3 (11%)	Not employed	03 (11%)
6.1 years-8 years	5 (18%)	Retired	09 (33%)
8.1 years – 10 years	5 (18%)	Reason for ICD	
		Long QT syndrome	5 (18%)
		Arrhythmia	12 (44%)
		Dilated	
		Cardiomyopathy	5 (18%)
		Heart Failure	3 (11%)
		Genetic conditions	2 (8%)

4.8 Study Interviews

Many participants requested to have the interview conducted in their own home, a number agreed to the interview following a clinic appointment in a room that was secured by the gatekeeper and a few requested to meet in a local hotel. One participant who had agreed to participate was contacted on several occasions but failed to respond. Two participants did not attend the prearranged interview. When contacted by the researcher to reschedule, they chose not to participate due to personal reasons. On one of those occasions, the researcher had driven a considerable distance to meet the participant who subsequently did not attend. On reflection, this proved a valuable lesson for the researcher going forward with future interviews and highlighted the importance of phoning participants in the morning before setting out on a journey.

Before each interview, the researcher spent some time preparing and the audio recording equipment was tested to ensure it was working properly. Before commencing each interview time was spent engaging in general conversation with participants. This included thanking participants for agreeing to participate in the research, providing an outline of the study, explaining the format and answering any questions.

Consent and demographic details were also obtained before commencing each interview (see appendix: 1D). The data protection measures, although described in the consent forms, were reiterated to participants on the day of their interview. Permission to audio record the interview was requested from each participant.

Participants were advised before the interview that should they become upset, they could terminate the interview at any time and an appointment for a consultation with a counsellor/ psychologist or a support group within the Irish heart foundation would be arranged. As this was an unstructured interview, participants were informed that one question would be asked: "Tell me what it is like for you to live with an implantable cardiac defibrillator" and were invited to continue speaking but advised that on occasions the researcher may interrupt to clarify or probe for additional information. An interview guide was also used (see appendix: 8). Throughout the interviews, the researcher used opportunities to encourage participants to continue talking by using open body language, eye contact, leaning in and nodding appropriately. Participants welcomed the opportunity to talk openly about their experience. Throughout the interviews, the researcher probed when further clarification was necessary. The researcher was conscious of the importance of remaining sensitive to participants' feelings and allowing adequate time to discuss emotive issues which may arise during the interviews. The interviews varied in duration from 10 minutes to 60 minutes and were discontinued when they came to a natural end. The 10-minute interview terminated as the participant stated 'that is all I have to say about the experience'. The participant had nothing more to add when probed. Short field notes were also recorded during the

process. After each interview memos were recorded in a journal; this included the researcher's initial thoughts on the first meeting, how the interview went, and what the researcher's initial interpretations were. This provided an opportunity to reflect on the overall interview. I was conscious that in order for my own interpretations to develop I needed to undertake a process of self-reflection. Transcriptionist tapes were labelled only with coded pseudonyms to protect confidentiality. The transcribed interviews were uploaded to NVivo, and analysis was undertaken in keeping with Ricoeur's analytical framework.

4.8.1 Reflection

As part of the research process once the interviews were completed I wrote notes in a journal. I felt it was necessary to do this while the interview was fresh in my mind. During one interview I became aware that the recorder was not displaying the time, on further inspection, it was confirmed that the device had turned itself off. This was an extremely embarrassing and uncomfortable situation. The participant quite quickly became aware of what had happened and insisted on beginning the interview again. I learned a valuable lesson, never to rely on technology and always have a backup method of recording. The duration of the interviews depended on the interviewees; some talked quite openly about their experience, while others had less to say, this was more evident in the older male participants who required additional prompting, for example, "can I take you back to when you said you were anxious" "or you talked about your family" one participant decided after eight minutes that he had said enough about living with the device and was adamant he was finished. A number of the participants requested I meet in their own homes; these were mainly females who had children and I was quite comfortable with this suggestion. These interviews were usually scheduled for the evening when their children were in bed however on one occasion one of the children got up, so the interview was paused for a period. We resumed when she had her child settled. One participant was quite hard of hearing and requested

their daughter was present. This did not present a problem as the daughter remained quietly in the corner and only became involved if she felt the dad did not hear something.

I was aware of an appropriate dress code before going to the interview. I did not want to appear too formal as I felt this might create a barrier between the participant and myself if they felt I appeared too overdressed, I was also conscious of not appearing too casual as this could appear to undermine the value and importance of the interview. I was aware that I should appear both professional and trustworthy. Instead, I chose to dress smart casual, I looked smart but most importantly appeared relaxed and confident. I feel this contributed to the formation of a relaxing environment. Interviewing requires many vital skills, I feel maintaining good eye contact throughout the interview is one of the most vitally important skills, the participant recognises that they are being listened to attentively and feel happy to continue talking.

As I continued with the interviews I felt my skills improved I became more comfortable and relaxed developing more confidence with probing. Overall, I enjoyed the interviewing component of the study. The interviewees were pleasant and willing to share their stories. I felt comfortable and found it easy to develop a rapport early in the interviews. Although, I informed all of the participants that my role was of a researcher many were aware of my nursing background having read the participant information leaflet before agreeing to participate therefore happy to meet and participate in the study. I questioned if perhaps because of my background history that many of the participants consented to participate in the study. I felt perhaps the answer to this question was yes, because of this I felt grateful. I was aware had I attempted to undertake the research without my previous knowledge participants may not have consented to participate. I also felt that my ability to build up a rapport quite early in the interview was a result of my previous background in

cardiology. A number expressed gratitude for the opportunity to talk about their experience with someone. However, I was equally aware of the sensitivity of their experiences and how the interview had the potential to evoke traumatic memories. A protocol was devised in the event of the participants becoming distressed (see appendix: 5). Throughout the interviews, they all appeared relaxed and comfortable speaking during the interview. At the end of the interview, I remained for a short period to share a cup of tea and general talk, I thanked them and either gave the participant a bottle of wine, a cake, sweets or Easter eggs for the children.

As a lone researcher, I was not uncomfortable travelling to people's homes the biggest challenge I found was finding their house. Some houses were in rural locations, and I did get lost on route needing to phone to get additional directions. I allowed extra time when travelling. I did, however, have a safety protocol in place in the event of any adverse situations occurring (see appendix: 9).

4.9 Data Analysis

Phenomenological analysis is characterised by a search for meaning that is directly or indirectly communicated within the data (Dahlberg, 2006). Various schools of phenomenology have proposed approaches to data analysis (Polit and Beck, 2006). These include Giorgi's search for a phenomenon's essential meaning structure (Giorgi, 2008) and IPA's less structured approach (Smith, Flowers and Larkin, 2009).

For this study, Paul Ricoeur's theory of interpretation, discussed in chapter three, was chosen as the analytical framework (Ricoeur, 1976). The researcher chose Ricoeur as it built on Heidegger's spiral of interpretation, moving from explanation to understanding. Ricoeur (1991b) recognises that human experience and understandings are interpretive. As the researcher's aim was to gain an in-depth understanding of the participant's experience of living with an ICD, Ricoeur's framework was deemed as an appropriate method to achieve this aim.

The stages of Ricoeur's theory of interpretation portray a broad understanding of the lived experience, consisting of a number of stages of interpretation: a naïve reading, naïve understanding and in-depth understanding and are discussed in detail in Chapter five: section 5.4 and 5.5).

4.10 Rigour in Qualitative Research

The consideration of rigour with regards to both validity and trustworthiness is a crucial element of conducting qualitative research (Koch, 1996; Sandelowski, 1986; Cypress, 2017; Daniel, 2019; DeWitt and Pleog, 2006; Lincoln and Guba, 1985), and demonstrates that the study is of genuine quality (Taylor, and Thomas-Gregory, 2015). The quality of qualitative research is often determined by trustworthiness (Baillie, 2015; Burns and Grove, 1999; Daniel, 2019) and lies in the richness of the description of the data. A method of addressing trustworthiness in qualitative research is by highlighting the necessity for studies to reveal credibility, transferability, dependability, and confirmability (Lincoln and Guba, 1985).

Lincoln and Guba's (1985) four criteria guided rigour was supported by the (TACT) framework (trustworthiness, auditability, credibility and transferability framework) (Daniel, 2019). The TACT framework can be utilised as a guide to understanding strategies for achieving rigour in qualitative research (Daniel, 2019), and provided a guide for addressing specific questions about the study to determine rigour.

4.10.1 Credibility

Credibility portrays an accurate representation of participants' lived experience (Cypress, 2017) by demonstrating assurances in the 'truth' of the findings (Polit and Beck, 2006; Pandey and Patnaik, 2014). A qualitative study can be deemed credible when it demonstrates rich descriptions or interpretations of the human experience (Sandelowski., 1986) The credibility of research findings can also be determined by the sampling decisions (Crookes and Davis, 2004).

The researcher demonstrated credibility within this study by a number of means, revealing how truthful the findings and interpretation of the findings were. The interviews were transcribed verbatim to text. Examples of each participant's quotes were provided that linked as closely as possible to the participant's lifeworld. Credibility was furthermore enhanced through the process of reflexivity. The researcher provided accounts of the experience as a researcher (Daniel, 2019). The researcher provided reflective accounts throughout all aspects of the study and acknowledged all previous background knowledge and beliefs held that could lead to potential bias. The prolonged engagement involved immersing in the world of the text which is keeping with Ricoeur's theory of interpretation remaining true to the methodology. Peer debriefing was achieved through ongoing support from the academic professionals in the university. Feedback from peers such as academic staff provides support and scholarly guidance and assists researchers to improve the quality which enhances credibility within a research study (Anney, 2014). The data collection, analysis and findings were subject to peer review by supervisors to confirm the accuracy of the findings. Nvivo 11 was used as a method of data management and demonstrated the decisions of analysis throughout the research process. Utilising this method provided clear evidence of the steps undertaken by the researcher throughout each stage of the analytic process. This is referred to in research as an audit trail and discussed in the section: 4.9.5. Research quality can be achieved by providing rich descriptions, reflexivity and audit trails which contribute to promoting rigour (Baille, 2015), and provides evidence that the study has been carefully carried out (Parahoo, 2006). Moreover, the quality of phenomenological research is assessed on its transparency (Balls, 2009).

4.10.2 Transferability

Transferability refers to the degree to which the findings can be transferred to other populations similar to those in the study (Parahoo, 2006). A study is transferable if the audit trail demonstrates a clear outline of the process

enacted by the researcher this could guide future researchers to enact a similar process.

The researcher demonstrated transferability by providing rich descriptions of the research process and clearly outlining the steps taken whilst conducting this study. Evidence of the study participants and demographics are provided. The participants recruited were knowledgeable about the phenomenon. Throughout the study, the researcher provided clear evidence of the steps enacted; knowledge of this may be useful to guide future researchers conducting similar studies. Conducting a pilot interview and outlining the steps enacted including reflexivity further demonstrated reflexivity. The balance of gender and the large sample size and the variance of age all demonstrate the transferability of the findings. This allows for transparency of the research path (Korstjens and Moser, 2018).

4.10.3 Dependability

Dependability verifies the consistency of the findings. One strategy to confirm dependability and conformability is an audit trail (Korstjens and Moser, 2018), achieved by verifying themes with a colleague (Cypress, 2017).

Dependability was achieved by providing a clear statement of the purpose of the study, the aims and objectives and an outline of the research design which was consistent with the underlying methodology. The approach to analysis chosen was appropriate for this study. The findings and interpretation reflect the underpinnings of the chosen methodology and are exemplified throughout the study.

4.10.4 Conformability

Conformability refers to the level of neutrality of the findings of a study, formed by the participants and not through the researcher's bias or interest. Conformability relies on other experts and participants agreeing with the researcher's interpretation (Parahoo, 2006). Expert verification is when an independent analysis is undertaken by an expert at the request of the

researcher (Taylor and Thomas-Gregory, 2015). However, as phenomenology recognises there are multiple interpretations of reality, this process may not be advised.

Conformability is further enhanced through reflexivity. A qualitative researcher needs to demonstrate self-awareness and reflection (Korstjens and Moser, 2018). Steps that assist in addressing reflexivity can be achieved through the use of a reflective journal to report any beliefs and values held by the researcher that may possibly influence the study process. A research diary can prove beneficial in creating an awareness of reflexivity (Baillie, 2015; Clarke, 2009; Nadin and Cassell, 2006).

The researcher demonstrated reflexivity through self-reflection a heightened awareness of fore-structures/presuppositional knowledge throughout each stage of conducting this study; for example, see chapter 3 section 3.4.1. Throughout this study, the researcher has reflected on prior knowledge and past influences to ensure reflexivity is interwoven from inception to conclusion.

Confirmability was enacted by Ricoeur's concept of distanciation, through distancing from the written text to remain objective and allow participants' voices to emerge. This entailed focusing solely on what the text was saying rather than what was verbalised during the interview. The process of peer debriefing assisted with this process by continuous review from my research supervisors.

However, the study is shaped through the participant's responses rather than the researcher's views. This was firstly enacted by entering a dialogue with participants conducting unstructured interviews to allow free flow discussion having a core question introducing prompts where necessary to stimulate discourse. Here the researcher listened attentively to the voices of participants. During the analysis process, revealing the world of the text involved standing back from the text and viewing objectivity adhering to Ricoeur's theory of distanciation.

4.10.5 Audit Trail

An audit trail clearly outlines the steps taken during the research process. Auditability is achieved by demonstrating a clear decision trail of the documentation used by the researcher during the study from start to finish (Carcary, 2009; Taylor and Thomas-Gregory, 2015). A vital aspect of an audit trail that aids in achieving rigour is the information on sample size, inclusion and exclusion criteria (Baillie, 2015). This was clearly demonstrated by the researcher within the study. The researcher demonstrated evidence of the audit trail by outlining the process of research decisions and how the study was conducted from start to finish. Chapter five provides an explicit account of the analytical decisions and processes employed in revealing the phenomena of interest for this research.

The study is shaped by participants' responses rather than the researcher's views or bias and reflected in the verbatim accounts provided. Minutes of supervisors' meetings, interview transcripts, coding, evidence of emerging themes and reflective notes were archived to provide transparency of the research path.

By addressing all of the above upholds research integrity and enhances the authenticity of the study (Daniel, 2019).

4.11 Conclusion

In this chapter, the researcher has outlined the study's ethical issues, sampling strategy, method of data collection, the process of analysis, and methods for ensuring rigour. Examples of self-reflection and reflexivity have been discussed and included throughout. The following chapter presents a detailed account of the process undertaken in analysing and interpreting the data.

Chapter Five: Illuminating the Experience

5.1 Introduction

The focus of this chapter demonstrates the decision trial of interpretation and outlines the process undertaken in analysing and interpreting the data using Ricoeur's Theory of Interpretation as an analytical framework (Ricoeur, 1981) as discussed in Chapter three, section 3.10 and Chapter 4, section 4.9. An overview of the findings is also presented.

In adhering to Ricoeur's (1981) theory of interpretation the process of analysis was performed on three levels: The following model, adapted from (Horrigan-Kelly, 2015) following guidance from Ben Meehan, NVivo trainer, (2015) was developed to assist the researcher throughout the process of analysis (see figure 5.1).

Table 5.1 Guide to Assist the Process of Analysis (Adapted from Horrigan Kelly, 2015).

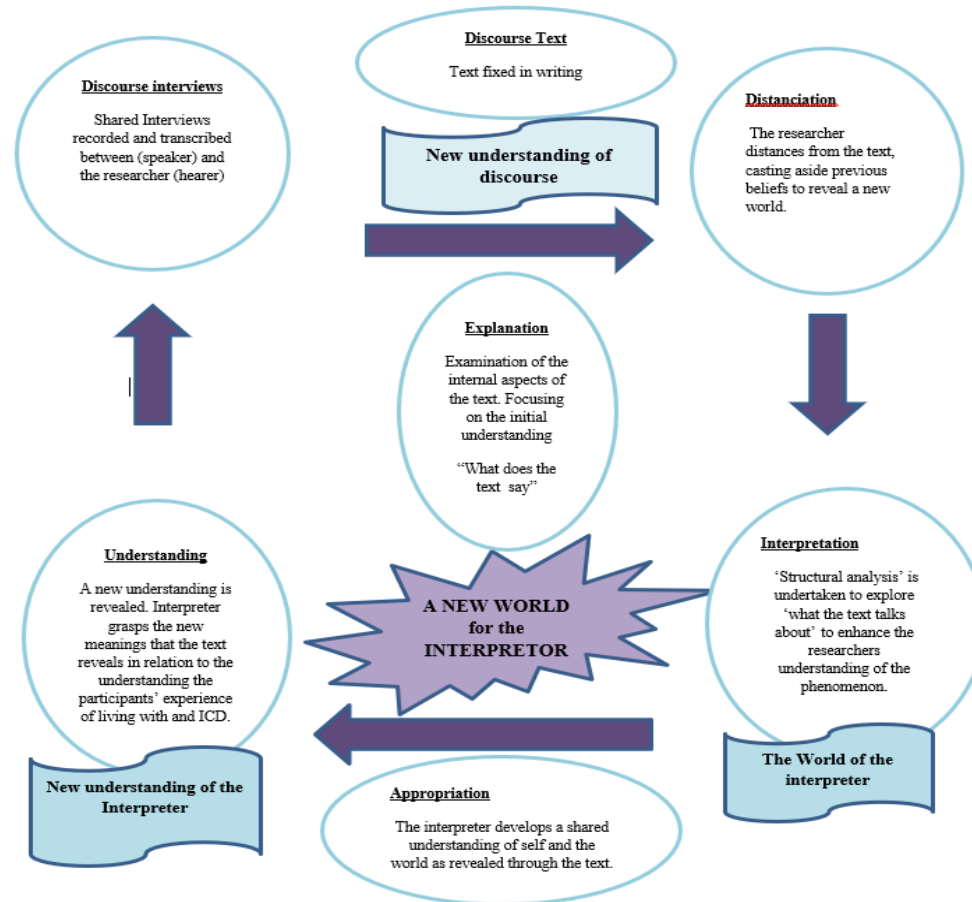
Ricoeur's theory <i>NVivo process</i>		Aspects of Ricoeur's theory enacted during the process of analysis.	Practical steps
Naïve reading	Phase 1 Transcripts imported into NVivo software package. Open coding.	Discourse Distanciation Explanation	Transcripts read and re-read. A distance was created between the interview and the written text. Standing objectively asking "What is the text actually saying". Highlighting and coding any keywords, groups of words or sentences. Identical words were coded together creating a new code for similar words.
Naïve understanding	Phase 2 The categorisation of the codes. Merging codes. Colour coding codes.	Appropriation Interpretation Understanding	The text divided into unit meanings were coded with appropriate wording. Similar codes were placed into categories and clusters. sub-themes created renamed merged and restructured.
In-depth understanding	Further reduction of the codes. Developing sub-themes and themes. Phase 3 Further reduction Of codes and Clarification of themes.		Exposed the overall themes and their meaning.

5.2 Ricoeur's theory of interpretation: A framework for analysis.

As explained in the previous chapter (chapter 3, section 3.10) Ricoeur's (1981) hermeneutical analytical stages frame this study and include the key stages, distanciation, appropriation, understanding, and interpretation.

A simplified description of the overall process of Ricoeur's (1981) theory of interpretation used in this study has been adapted from (Ghasemi et al., 2011; Horrigan-Kelly, 2015; Tan, Wilson and Olver, 2009) and outlined in figure 5.1 below.

Figure 5.1 A Simplified Description of The Overall Process of Ricoeur's (1981) Theory of Interpretation



5.3 Reflexivity

Before commencing analysis, it was necessary for reflection and exploration of my own personal fore-structures of understanding, in keeping with Heidegger's philosophical principles and Ricoeur's ideal of acknowledging presuppositional knowledge for one to have a heightened awareness of their worldviews (Heidegger, 1962; Ricoeur, 1981). An outline of my personal fore-structures of understanding/ presuppositional knowledge is presented below.

5.3.1 Researcher's personal fore-Structures of Understanding

I held mixed beliefs concerning individuals who had ICDs implanted. I felt they were probably cautious when carrying out their activities following implant. However, I believed they were also relieved to have their device.

5.3.2 Researcher's Professional Knowledge and Experience

Although I had background knowledge of the cardiac conditions associated with ICD implants I had little knowledge of the effects it had on individual lives and families. I was unfamiliar with the available support services until I embarked on this study.

Following reflection, I acknowledged my presuppositional knowledge; to dismiss this knowledge would be inappropriate and impossible to suppress. My assumptions of 'what it is like to live with an ICD' are based on two decades of working within the field of cardiology. Additionally, I felt it necessary to explore and analyse my personal orientation in order to provide an understanding of what influenced my choice of study topic.

However, although I am aware of this background knowledge I am cognizant of my role as a researcher within this study. Whilst I suspect what it may be like for participants to live with their device I have no true knowledge.

During the interview process, I was conscious to refrain from providing advice or opinions in relation to their ICD. Throughout the interview, analysis and writing process I maintained a heightened awareness of this knowledge and made notes in my research journal of situations that became challenging. During the process of analysis, I was conscious of focusing solely on ‘what the text was saying’ rather than trying to focus on my own beliefs. This awareness helped shape my analytical approach. In a further attempt to remain unbiased I chose to avoid reviewing the literature until the analysis of the participant’s interviews was completed.

5.4 Phase 1 Analysis: Naïve Reading (Explanation)

The first phase of Ricoeur’s (1981) theory of interpretation is Naïve reading. The voice recordings of each interview were individually transcribed verbatim to text. While the process of transcription is not acknowledged as a key phase of Ricoeur’s (1981) interpretive theory it allows the researcher to become immersed in the data becoming familiar with the text as it was written. Transcripts were uploaded to NVivo 11, and pseudo names were allocated to ensure confidentiality and protect participants’ identity (see chapter 4. section 4.2). Following this, each transcript was checked and read for accuracy. Once the data was transcribed the text now took the place of speech and it was at this point that phase one of Ricoeur’s analytical framework was employed (Ricoeur, 1981).

The naïve reading (phase 1) focuses on forming an initial understanding of the text as a whole (Ghasemi et al., 2011; Lindseth and Norberg, 2004; Simony et al., 2018). This phase of analysis involved the researcher reading and rereading the written text asking of this text ‘what does it say’. Ricoeur (1991) argues that “Text is discourse fixed in writing”, referring to transcripts as live text being converted to writing. Ricoeur (1981) recognised that discourse is altered when speech is converted to writing. During this phase, distanciation was enacted to create a distance from the interview and written text. In enacting distanciation the researcher cast aside previous beliefs and knowledge in order to focus on what the text was

saying as outlined in section 5.3.1. This heightened awareness facilitated the objectivity necessary to enact the process of distancing as advocated by Ricoeur, (1981), that is, standing back objectively from the text while asking of the text ‘what does it actually say’. Here the researcher was distanced from the speaker and the interview suspending all previous fore structures of knowledge focusing on reading the text as a whole. This meant being unbiased with a heightened awareness of any personal fore structures of understanding whilst undertaking this analytical process. Being aware of fore structures and preunderstanding assists the researcher in shaping their interpretation. It is important to remain unprejudiced as a researcher however still being conscious of my own “fore structures of understanding” (see reflection; 5.3.1). This enabled the researcher to “guess” (Ricoeur, 1991) what the text was saying and grasp what the experience of living with an ICD was like for the individual. This space enabled the researcher to focus solely on the text. The text distances itself from the narrator it takes on a new life of its own (Simony et al., 2018).

After the initial reading, the researcher explored the preliminary explanation of what the text says with the focus of revealing a view of “being in the world” for an individual living with an ICD” as voiced by participants now written in text. This involved highlighting and coding any keywords groups of words or sentences that revealed anything concerning the participant's experiences of living with an ICD. The codes that were created remained as close to the participant's language as possible (see figure 5.2).



Figure 5.2 Naive Reading Initial Codes

This process did not involve interpretation; it purely identified words that were coded to free nodes in an unorganised manner using the NVivo management package. Identical words were coded together creating a new code for similar words as the coding continued the text was explored concerning new data emerging that had not previously arisen. More than seven hundred codes were created. These codes revealed how participants experience a mix of emotions living with this device. There was an array of emotions revealed. The fear associated with anxiety led to depression. Many expressed gratitude at surviving a cardiac arrest and being alive, however uncertain about receiving a shock from the device and their future. They felt isolated on occasions and found resonance in isolating themselves. Younger individuals found the transition more challenging. They became dependant on others and expressed feeling unsupported by the services. This was more prevalent in participants residing in rural areas. Participants revealed how they were financially burdened and worried about losing their livelihood. They found the experience life-changing and noted how they learned over

time to adapt and adjust their lifestyle in order to cope. Eventually, they began to accept the ICD as part of their life.

Before advancing to phase two, reading and re-reading of the text on several occasions was undertaken, further examining the text for any additional significant comments related to the participant's experience of 'Being in the world' and living with an ICD. Following the completion of naive reading and a preliminary explanation of what the text says, meanings and thoughts requiring further analysis were formulated. The preliminary explanation of what the text says revealed a sense of dissatisfaction with the location of services. Participants living in rural settings felt disadvantaged in comparison with those living in urban areas. They felt there was a lack of specialised support locally. Following discharge from the hospital, they were repeatedly referred to services including support groups based in Dublin. All participants highly commended the support of the nurses, technicians and medical team involved in their care whilst in the hospital and during follow up appointments. It was the difficulty accessing and attending services that caused the greatest concern in relation to both travel and finance.

5.5 Phase 2: Naïve Understanding and Interpretation Structural Analysis

Following on from phase one of the analytical process exploring 'what the text says', the stage 'structural analyses were undertaken to explore 'what the text talks about' (Ricoeur, 1976). The purpose of the structural analysis is to reveal the text as a whole. During this process, the researcher identified sections of text that revealed specific aspects of "what the text talks about" and split into unit meanings relevant to participants' lived experience. This provided a vision for the preliminary interpretation of the whole (Soderberg and Norberb, 1993).

During this stage of naive understanding key sentences were reviewed and questions on what the sentence reveals. The section of text divided into unit meanings were coded with appropriate wording using NVivo 11(QRS

international, 2016). The unit meaning refers to a part of the text that suggests one meaning (Lindseth and Norberg, 2004). The unit meanings were reread and scrutinised for similarities and differences. Throughout this process, the focus was on identifying significant text that represented the individual's unique experience and divided into unit meanings. The highlighted sentences and paragraphs which described specific selected phenomena and divided into unit meanings are outlined below (see figure 5.3 below).

Figure 5.3 Example of Structural Analysis (Adapted from Ghasemi et al., 2011; Horrigan-Kelly, 2015; Lindseth and Norberg, 2004)

Meaning unit	Condensation	Researcher memo	Naïve Reading Sub-themes	Naïve Understanding Themes
<p>Nick: I don't remember now much about the time, but as we met the ambulance I got another shock. I got 16 or 17 shocks whilst inside, between 6 o'clock in the morning and 11 o'clock, I was in the resuscitation room in the hospital, and it might have been 11 o'clock before I was stabilized. I think my magnesium ran low, they were pumping that stuff into me, and it was taking so long. I was hooked up to an external defibrillator and I had the defibrillator inside me, and it kept going off. I was counting, it was every 20 minutes, every 30 minutes I was getting worried because every time I was going, I would just go completely blank, I was gone. It was, it just felt like I was sinking underwater and then with a bang like someone was hitting you with a sledge in the chest and you were coming back. You are trying to get your breath</p>	<p>This section of the text reveals the sense of being towards death. It reveals the fears and uncertainty surrounding it. The descriptions of the sensation of dying. How that moment changed his life forever.</p>	<p>When I arrived, the participant revealed that they were nervous and not good at talking but willing to answer any questions. I explained I would ask one question "Can you tell me what the experience has been for you living with an implantable defibrillator"? They began talking so eloquently and amazed me with their story.</p>	<p>Being resuscitated. Being shocked by the device Being worried. Being gone. Being a life-changing moment.</p>	<p>Being towards Death</p>

<p>again, but I knew from all the defibrillator readings that the batteries were starting to go., so I was counting how many shocks could be left before it would go dead. I was worried, but I was hooked up ready for an external defibrillator anyway if the other one didn't work. This was worrying me a lot, throughout the whole event. I think it was maybe after 11 o'clock before I got stabilized and they got me settled again. I didn't feel great after that. I knew it was a kind of a life-changing moment, I had to change my lifestyle then, so..., I never drank since that day I changed my lifestyle.</p> <p>Nini: I think the biggest change for me, was just the fear of the unknown, is it going to happen again. I just had an awful fear of dying. I definitely began to isolate myself from everyone. I didn't want to go out to parties or be with friends.</p>	<p>This section refers to the fears and uncertainty associated with living with the device.</p>	<p>When I arrived Nini was so welcoming. I brought cakes. She began to describe her experience from the initial diagnosis. She highlighted how impressed she was at the way the consultant took time to sit by her bedside and explain everything in detail before insertion. The flow of the interview was natural and provided an excellent overview of the participant's experience.</p>	<p>Being uncertain. Being isolated. Being frightened. Being young.</p>	<p>Being towards death. Being robbed of their Identity Being a Struggle with emotions</p>
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The identified meaning units were further condensed and merged creating provisional clusters in order to make sense of the data and its meaning. Similar codes were placed into categories and clusters. Patterns began to emerge, and sub-themes were created renamed merged and restructured (see figure 5.4). This process was repeated several times for clarification. Throughout the process, the researcher was conscious of any interrelationships or similar events developing within the codes and categories to recognise evidence of data saturation. As the process continued and the phenomena became more consistent, categories began to emerge and overlap, no new data appeared to come forward and data saturation became more evident. Within the process of inquiry, saturation builds rich data (Morse, 2015). Finally, clusters of free nodes were grouped into themes initially and then sub-themes that best captured the phenomena of interest. Each participant's description was compared and contrasted in order to clarify the essential themes.

Participants revealed concerns about dying and being told they had a condition known as sudden death syndrome and questioned how the device would respond if they did actually die. They recounted the experience of when they had a cardiac arrest and their ICD activated and being resuscitated led them to focus on thoughts of death and dying. Following the merging of the sub-themes the theme "being towards death" was created. An example of some codes which were merged during the process of analysis is illustrated in figure (5.4) below.

Figure 5.4 Codes Merged

Phase 2 - Naive Understanding					
Name	Sources	References	Created On	Cn	
BEING TOWARDS DEATH		13	36	23/09/2018 13:15	01
SAVED MY LIFE		0	0	24/10/2018 23:55	01
BEING CONCERNED ABOUT DYING		0	0	24/10/2018 23:57	01
BEING SUDDEN DEATH SYNDROM		1	1	16/10/2018 00:46	01
BEING WANTING IT REMOVED WHEN I DIE		1	4	13/09/2018 18:22	01
WHAT HAPPENS IF I ACTUALLY DIED		1	1	13/09/2018 18:22	01
BEING RESUSATATED		1	1	24/10/2018 15:56	01
ICD BEING ACTIVATED		7	12	16/10/2018 00:48	01

In addition to undertaking this process using NVivo software, the researcher also chose to manually carry out the process. All open codes created during phase one were also copied and pasted onto a word document, resulting in fifteen pages of A4 nodes, colour coded on the computer and also with a highlighter pen then placed into categories further condensed sub-themes and themes developed to further illuminate the opening coding (see Appendix; 17).

At this stage of the analysis, seven key themes and subthemes were identified that exposed the meaning of living with a cardiac implantable defibrillator (see Table 5.2).

What appeared to concern the majority of participants and have a major impact on their lives was being restricted physically, being unable to drive and work which led to a dependency on others, all of which contributed to the theme ‘loss of identity’. Participants revealed how they experienced a variety of conflicting emotions from shock, anxiety, fear, uncertainty and stress to gratitude and relief resulting in the theme ‘struggling with conflicting emotions’.

Many conveyed how they experienced great support from family and friends whilst a number revealed they would have appreciated more information and support from healthcare professionals and services. This

contributed to the theme ‘being supported and informed’. A number of participants revealed how they were haunted by events of the past, being resuscitated following a cardiac arrest, which contributed to fears of death and dying resulting in the theme ‘being towards death’. Participants also revealed the difficulties they endured whilst struggling to accept and adapt to this life-changing event emphasising that time contributed to their acceptance, this resulted in the final theme emerging, ‘being on a journey of acceptance’. Table 5.2 outlines the initial themes and sub-themes identified.

Table 5.2 Initial Seven Themes and Subthemes that Emerged

THEMES	SUB-THEME
Losing one's identity	Being unable to drive. Being unable to work, Being restricted in physical activities. Being dependant on others.
Struggling with conflicting emotions.	Being psychologically affected, Being life-changing. Being afraid. Being thankful. Being anxious. Being scared. Being worried
Being financially burdened,	Being dependant on others. Being financially burdened. Being unable to return to the original job. Needing to get a taxi.
Being supported and informed,	Being uninformed. Being unsupported by services. No information is given. Feeling isolated. Being supported.
Being shaped by past experience,	Frightened of getting a shock. Had a cardiac arrest in the past. Being resuscitated. Never wanting their family to witness this again.
Being towards death,	Being afraid of dying. Concerns about the ICD reactivating after death. Having a near-death experience.
Being on a journey of acceptance,	Being unable to accept. Being life-changing Being accepting, being easier with the passage of time.

This stage entailed exploring the text in detail to reveal tentative meaning units “what the text talked about” and was completed to enhance my understanding of the phenomenon of “living in the world with an ICD”. Completion of this process contributed to the validation of the tentative themes identified during the structural analysis resulting in the development of units of meaning and significance (Ricoeur, 1981; Tan, Wilson and Olver, 2009).

5.6 Phase 3: In-depth Understanding (Interpretation)

The final phase of the interpretation was to uncover the overall themes and their meaning that revealed the meaning of what the experience is like for an individual to live with an ICD. Ricoeur refers to this as appropriating the text; “making something one’s own” (Ghasemi et al., 2011). During this phase of the analysis, the researcher moved backwards and forwards between explanation and interpretation and between interpretation and explanation to gain a deeper understanding of what the text was saying in keeping with the experience of living with an ICD. Subsequent interpretation involved the researcher continuously rereading and questioning the text, gaining an initial grasp to acquiring a more in-depth understanding whilst moving between explanation and understanding. Similar to Heidegger’s hermeneutic circle, Ricoeur’s hermeneutic arc moves forward and backward, never-ending, through this thorough interaction the phenomenon is unveiled (Charalambous, Papadopoulos and Beadsmoore, 2008).

This practical approach involved the researcher revisiting the subthemes and themes focusing on the context on which they were founded, linking the researcher’s fore structures of understanding beliefs and experiences, participants’ experiences, and understanding from the relevant literature. Interpretation of information external to the text contributes to the text becoming a living communication (Tan, Wilson and Olver, 2009). Reflecting on the initial reading and this phase of the interpretation resulted in the research achieving a more comprehensive understanding of the findings. This enabled the researcher to reveal a reconfigured account of what it is to be in the participant’s world beyond the original meanings intended. Simony et al., (2018) recognise this final phase as achieving appropriation of the data.

However, on revisiting the data, the researcher chose to carry out a further review which resulted in the original seven themes being merged to become three. ‘Losing one’s identity’ and ‘being shaped by past experience’ merged as subthemes with the theme ‘being toward death’. ‘Being a struggle with

emotions' and 'financially burdened' merged as a sub-theme with the theme 'being on a journey of acceptance'.

The three key themes identified during this stage of analysis revealing naïve understanding were 'being supported and informed', 'being towards death' and 'being on a journey of acceptance' and are illustrated in the graphs below figure 5.5. with associated sub-themes.

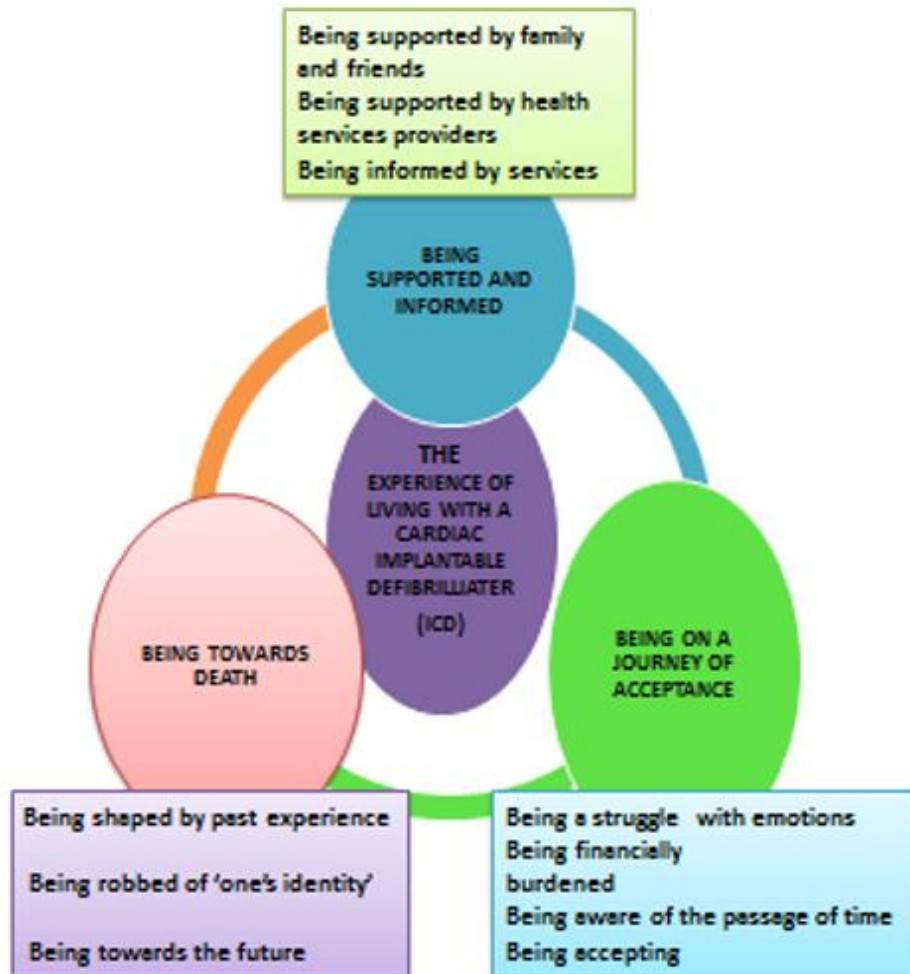


Figure 5.5 Final Themes and Sub-themes Identified

5.7 Being Supported and Informed

The theme 'being supported and informed' represents participants' view of being informed and supported following the insertion of their ICD. Views and concerns were voiced concerning the support and lack of support received from services they encountered throughout their journey. Lack of support was more evident from those participants residing in rural areas. Concerns were raised by many participants relating to lack of information provided pre-implant and a lack of support post-implant. The need for more structured support by specialist health care professionals was highlighted. Participants acknowledged the need for local support groups, which could provide them with an opportunity to share and compare their experience with others. Many of the participants had been given a home monitor which allowed them to record events, this they felt provided them with the comfort of knowing they had the available care and support without the need to travel miles to the regional hospital.

Heidegger's, (2001/2008) concept of "being-with" is a characteristic of each individual Dasein "being in the world" and also our "being with others". Heidegger perceives Dasein as an essential aspect of human existence (Gallagher and Jacobson, 2012). As entities of the world, Heidegger, (2001/2008) asserted we alone do not contribute to our Dasein (our being-in-the-world), others also contribute to this process of living, and we are unable to separate ourselves from this interaction. Participants acknowledge the need for "being with" and being supported by others such as family and friend's support. They felt they were no longer free to live as they had previously. This theme from a Heideggerian stance represents "being in the world" "being towards others, "Care" and "Authentic vs. Inauthentic" existence. Heidegger recognised that we live in a world authentically inauthentically or indifferently (Conroy, 2003). The Authentic manner in which their life was lived was consistent and based on their beliefs culture and habits. Now for some, because of their near-death experience, participants felt curtailed and challenged worrying about the uncertainty of their future.

5.8 Being Towards Death

The theme, 'being towards death' reflects participants' experience of having been told they had sudden death syndrome. Some had suffered a cardiac arrest and needed to be resuscitated, others feared that they may have a cardiac arrest. Before they needed an implantable cardiac defibrillator many of the participants led normal independent lives; they were mothers, fathers, husbands and wives. When faced with this implant normal everyday chores which they took for granted became an effort. Although their original identity remained preserved, their life had suddenly changed, and their bodies felt and looked different. This was notable in female participants as they were conscious they looked different because of their scar. They had to wear different clothes in order to feel comfortable, they no longer could participate in their normal everyday household chores and activities, care for their children, work or drive. Physically they felt restricted needing to depend on others for support. Their freedom to live life as they once had lived was inhibited due to their body restrictions (Kelly, 2014). Some participants voiced concerns about death and dying. This is reflected in Heidegger's concept of 'being towards death' and 'being to an end'. Death lies before us as something impending (Heidegger, 2001/2008). Many participants revealed unpleasant memories associated with past events, therefore they found it difficult to plan and consider a future as a result of this uncertainty. Once again Heidegger's (2001/2008) philosophy of 'being' recognises that certain modes of concern relate to the everydayness of being in the world, allowing the entities which are of concern to come to the fore, concerning ourselves with the entities that are ready-to-hand when met with something unusual. Eventually, participants developed a coping mechanism that assisted in adjusting and adapting and eventually led them towards acceptance. Heidegger acknowledged that accepting we will die someday, sets us free to go and live our lives (Kelly, 2014).

5.9 Being on A Journey of Acceptance

The theme 'being on a journey of acceptance' alluded to how participants struggled with their emotions in the early period following implantation.

Participants referred to periods of anxiety and depression, feeling scared and isolated. Revealing that they were restricted physically in the early days post-implant, they were afraid to lift their arm to shower or wash their hair. However, some revealed that they were grateful to be alive as family members had not been as fortunate. Some referred to feelings of guilt, saddened by the fact that their relative had not had this opportunity to get a device and had died. Participants also referred to the economic burden associated with their experience of having an ICD. This impacted on their ability to drive and work, with some having to leave their original job and seek alternate employment. This affected those living in rural locations more so than urban areas. Attending regular hospital and doctors' appointments also contributed to this.

Participants recognised that the passage of time made it easier to accept life with an ICD. Recognising acceptance took time, although they may have recovered physically, psychologically this took much longer. This theme from a Heideggerian perspective reflects the view of "being in" "being in the world" "being the future" and "being-toward-the-whole," and relates to the participant's experience of living in the world with an ICD. They recognised that they were now a "being" in the world with this new object and in order to survive in this world and have a future they must learn to accept in order to become whole again. The existence of time contributed to them learning to live a full life again contributed to this. Heidegger stresses the importance of recognising that we exist within the flow of time, we can either use it or waste it (Stenner, 1998). Through acceptance, participants moved forward to the present leaving their past behind making plans for the future.

5.10 Conclusion

This chapter has outlined the process of analysing and interpreting the data. This analytical process allowed the researcher to develop a greater understanding of the participant's experience of living with an ICD. Following an in-depth examination of the phenomenological findings, questions arose concerning what effect living with an ICD had on

participants' lives. How did they accept having this device? How much did they understand concerning the purpose of their device? How did they learn to adapt? What structures were necessary to assist or support them on their journey of recovery? These questions led the researcher to explore the phenomenon in more detail in order to acquire a greater sense of the meaning participants associated with their experience. The following chapter discusses the analytical findings that emerged in more detail.

Chapter Six: Findings

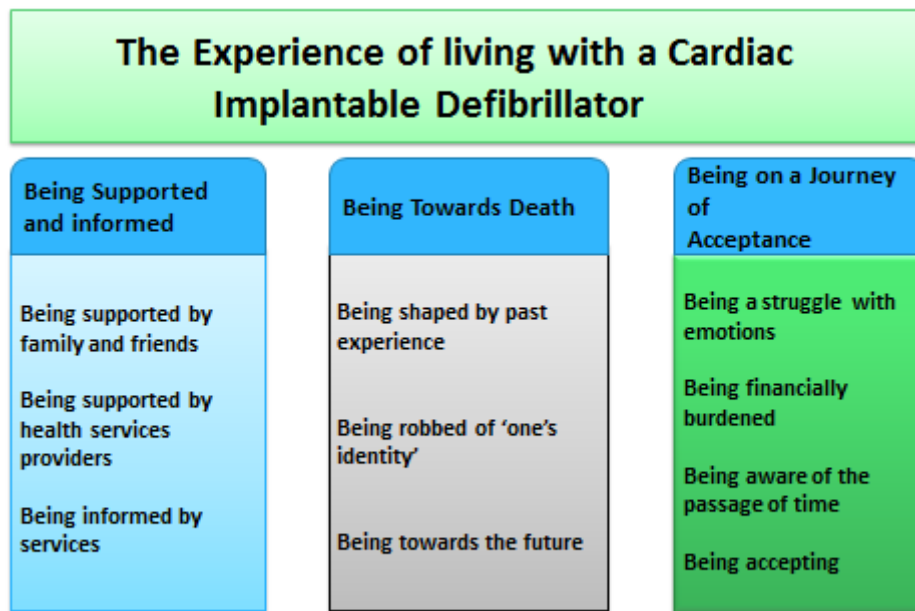
6.1 Introduction

This chapter focuses on the phenomenological findings of the participants' experience of living with an implantable cardiac defibrillator (ICD) displaying Ricoeur's (1981) interpretive phase of naïve understanding. The phenomenon of living with an ICD is underpinned by an unexpected and shocking forced robbery of one's identity and thrown on a journey where a struggle with 'being towards death' dominates before acceptance is accommodated as a result of support and information. Support from family, friends and health care professionals are central to the shift of 'being toward the future' but 'being towards death' is always a threat.

These findings are presented in the context of Heidegger's structure "being in the world" revealing what it is like for the participants of this study to exist in the world with an ICD.

The following section provides an overview of the key themes and sub-themes in more detail (Figure 6.1).

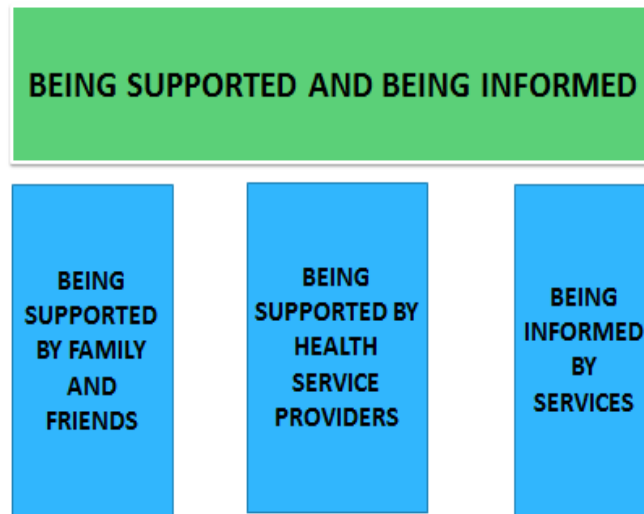
Figure 6.1 Themes and Sub-Themes Developed During The Analysis



6.2 Being Supported and Informed

'Being supported and informed' was one of the key themes that emerged revealing the participant's experiences in relation to the support they received from family, the health care providers and information they received from the services. This theme incorporates three subthemes, 'being supported by family and friends', 'being supported by health service providers' and 'being informed by services'.

Figure 6.2 Thematic Representation of Being Supported and Being Informed



Participants expressed concerns in relation to being supported and informed particularly in the early days following implant. A number revealed positive aspects whilst others emphasised negative areas of the support encountered throughout their journey. The importance of care, being cared for and referred to the appropriate care was emphasised by participants. Participants spoke about how the experience impacted on their family and friends and how they felt concerning this. Although all were grateful for the support they received from family and friends some felt they were expecting too much. In relation to support from other services their responses varied and were dependant on the particular site, they received their care. Their age and position in life appeared to determine their level of dissatisfaction with services. This resulted in mixed views amongst participants. Older retired participants appeared more relaxed and accepting of the support and information provided. Younger working participants with young children felt they required more support and information, particularly during the initial period.

Many study participants noted the lack of available support groups. While a number of others attended a support group initially, they did not experience

a benefit and chose not to return. Participants alluded to the lack of information received concerning their ICD pre and post-implant. Some participants believed organisations should provide information and support following such a life-changing event, but this was found in many participants' experiences were not the case. Many participants spoke about the methods they chose to assist them source information to inform themselves which commonly included internet search engines such as Google, support groups or referral to specialist units. The following section addresses the sub-theme 'being supported by family and friends'.

6.2.1 Being Supported by Family and Friends

This sub-theme represents participants' experiences of being supported by others. Many revealed their need and gratitude for support, especially in the early days following the initial diagnosis and implant. Participants acknowledged the support they received from others such as family and friends they clearly welcomed support during these vulnerable times in their life. While the importance of family support was emphasised, the over-reliance on family and friends for support left some participants feeling inadequate and expressed by one as "being useless". As time progressed they became less dependent.

Nick revealed that he was living abroad illegally without medical insurance, fortunately, he had a cousin living there too that managed to get him medical support.

"I have a cousin a pharmacist, with a medical background, she had connections with a few hospitals out there she advised me to get a second opinion from another Cardiologist in New York. I did and was told I needed an ICD because of my long QT readings. 'I was advised to attend another hospital where I had a defibrillator implanted within 3 days'" Nick

Alyson acknowledged how she had received great support from her friends in the initial period following discharge from hospital. They called every

day and brought dinners, while others lit fires, leaving her feeling guilty about depending on others.

“I found the first week quite hard. I was depending on people coming in 24/7. I couldn’t expect this to continue. One friend fed us for almost four weeks; another came in and lit the fire. My husband’s family was great but there was only so much they could do as they were working full-time, I had sisters-in-law and even brothers-in-law coming in to help, my sister also was a great help”
Alyson

Roisin acknowledged the support of her husband and parents. She also complimented her friends for their support. They devised a rota amongst themselves, which involved collecting her and bringing her to lunch. This continued for a period of six months following the device implant.

“My family and my husband were great support after I had the cardiac arrest; my husband probably took most of the brunt with the kids, supported by my parents. My friends didn’t want me to become “a cardiac cripple” or affected psychologically by the event so they actually did a rota for nearly 6 months. I couldn’t drive; one of them came up twice a week to bring me out for coffee or bring lunch. There is no public transport where I live so basically you need a car to get everywhere, you can’t walk anywhere.” Roisin.

Sofia had a similar experience with family and friends.

“Family and friends were great. I was very lucky to have my partner’s family living locally and they helped me out. I didn’t particularly want them coming all the way down here although it is not that far. The girls I worked with were great when I got to work they would take the kids to school” Sofia.

However, some participants expressed feelings of guilt and others felt out of control because of being dependant on the support.

“I felt guilty asking for help, the family is great, they are all as good as gold to us, but you just hate torturing people. But funny enough if anyone asked me for help I would be away like a shot”. Sarah

“I was dependent on other people for many things, to collect the kids from school and other places. I felt I was not in control of my life. Normally I am an organised person. I’m very in control; I became very dependent on people. Once I was driving things became a lot easier” Lilly.

6.2.2 Being Supported by Health Services Providers

Participants held conflicting views regarding the support they received from the wider hospital and community services. Some participants felt they were well supported whilst others, mainly those who were younger, felt that support was absent. Many revealed their need for specialised support especially in the early days following the initial diagnosis and post-implant, especially those living in rural communities. They alluded to the need for support groups and counselling services.

“I was very aware of the lack of professional support. I definitely think a counselling service or a person to talk to is necessary. It was a new experience. I think therapy would have helped me to cope a bit better as I was only 16 years old when I was diagnosed. This came as a shock; especially as my whole family were also diagnosed with the same condition” Nini.

Participants referred to the difficulties they had accessing medical support.

“I appreciate that the medical team don’t want people coming clogging up clinics when you have nothing wrong with you, but I think for reassurance if you were seen by a Consultant once a year it would be helpful. I did try to access the Consultant privately, but I was told that once I was attending the public clinic he wouldn’t be able to see me privately. I did, however, manage to get referred to cardiac rehabilitation which was a great support” Roisin

Maria was upset by the doctor suggesting that it was in her head.

“The doctor asked, how are you feeling, I replied awful and then when I tried to describe how I was feeling, which was very difficult to do, his response, was, have you spoke with a psychiatrist? He tried to tell me that it was all in my head. I said I know how I’m feeling. He replied it’s just that you get very upset. I said I am never upset before it happens; I get upset after it happens” Maria.

Jessie’s experience was similar to Maria’s, and she also felt she was not taken seriously.

“I had been to the doctor several times with palpitations, and I felt they didn’t really take me seriously despite my family history” Jessie.

A lack of medical support locally was alluded to by participants.

“When I go to the Doctors they are cautious, they won’t do anything. They advise me to contact Dublin. Doctors in Dublin have no concept how faraway Donegal is and the lack of resources that are available, we are isolated living in the country” Sofia.

“When I attend my local hospital, I get sent on to Dublin ... adjustments were made a few days later it started activating again, I contacted the local hospital again, through the same course, attend the local hospital and again back to Dublin..... I felt there was very little support here locally at that time” Sean.

Those participants who lived in the city had a better experience feeling they were in close proximity to a number of hospitals which was a relief. Those who were attending the specialised units felt they had great support through email or phone.

“I am lucky, I live 15 minutes away from most hospitals, living in Dublin I am 15 minutes from St James’s Hospital, 15 minutes from

Tallaght Hospital, 15 minutes from Crumlin Hospital, I am on all the bus routes” Laura.

“I must say everything was made quite clear for me. I had a couple of questions from my work as I would use certain tools like cauterised or drills. I felt I was able to contact the unit and they clarified everything for me” Jessie.

Again, Carla had a similar experience and felt the support was great and could link into Dublin at any time and got an immediate response.

“I have been so lucky I have great support even though I live in the country I have a link to Dublin. If you have any queries, you just email and you get a response the next morning, it is not a problem” Carla.

There were conflicting views in relation to support groups, a number of participants found it helpful, and others found it unhelpful. Others would have liked access but found there was none available in their area.

“There is nothing in Donegal, to be honest. Not that I am aware of anyway” Jessie.

“The aftercare is relatively non-existent. I know there are ICD support groups. And I have been thinking about, but it is on in Dublin, everything is in Dublin. There are a lot more people in the country with it than just in Dublin” Kyle.

Some participants were not in favour of the support groups as they found that either the other members were older, had different cardiac conditions or they used the forum as a venue to complain.

“I got involved with the Long QT Support Group and the ICD support group through the Irish Heart Foundation, I found it quite difficult at the time as the I.C.D. Support Group members were older and I was only young. Many of them were terrified to leave the house, as they had previous shocks, they had different cardiac

conditions like they had diseased hearts and you know different cardiac issues so their machines were firing all the time kind of, I couldn't deal with the I.C.D. Support Group for a long time” Laura.

“I did attend a support group in the beginning. It was through the Irish heart foundation. I found everyone complaining, it was a mess. So, I stopped going to those meetings” Martin.

6.2.3 Being Informed by Services

The experience of ‘being informed by services’ varied across participants and was viewed as receiving specific information as opposed to receiving support. Some were given information and literature prior to the implant while in hospital, however many revealed that they had not received information. Others would have welcomed more information, and some were content with what they received. Participants voiced that they would have benefited from more structured advice on discharge. This appeared more prevalent in the participants living in rural locations rather than those who attended larger centres. A number of participants revealed how they felt isolated because of their device but also had isolated themselves, this was partially due to the unknown and uncertainty associated with the device. This appeared more concerning to younger participants and those attending a rural hospital. Some participants claimed to have a lack of knowledge about their device initially and relied on Google for information. They were positive about their hospital experience but were disappointed with the post-discharge phase. Some participants expressed the need for a home visit from a nurse post-discharge as they were unable to drive, had young children and lived a distance from a bus route. Participants referred to the need for specialised support locally as a contact regarding information, which they speculated could reduce their feelings of anxiety, fear and isolation. This lack of information was equally evident for their family members. Participants expressed gratitude for the support they received from family in relation to the assistance with the children and home life. However, family and friends lacked knowledge and understanding of how the device functioned and what to expect or what not to expect. As a result

of their families' limited understanding, they were also anxious and restricted in the type of psychological support they could provide.

Kyle revealed how following discharge he was driven home by his mother from Dublin, and he received a text message on his phone which caused his phone to bleep. His mother pulled over in a panic thinking his device had gone off. His mother's reaction increased his fears.

“My mother was driving me home from Dublin when a friend text to enquire how I was. She pulled over and stopped the car and almost had a heart attack thinking the thing went off. I didn't know to laugh or cry. The fact that she was so anxious didn't help me” Kyle.

A number of participants revealed how they received little information pre-implant. They were given a leaflet and discharged home. They felt anxious about going home. Some revealed how they had to rely on Google for their information as there were no booklets available at the time.

“Pre-implant, I found very little information. It happened and was over before I knew what had happened. I had it in and there it was. I was given a leaflet going home with all the information about what was inside your body, but at the same time, I did not know what it was” Sean.

“I had the device implanted and I knew nothing about it. Unfortunately, Google is not the best place to be looking for information; they did apologize and said they didn't have the booklet at the time to go with it” Maura

“I was 25 years of age when I got it, I didn't really know much about them. I originally thought this was a pacemaker, I didn't realize it was actually a defibrillator. It did both jobs. I was given a booklet I wasn't told much apart from you are in for an ICD tomorrow morning, at 8 am, bang! That's it, you are left scratching your head. And the one thing everyone does is go on Mr Google, to get all the information about it. I was given a booklet on discharge

Living with an ICD – and on the front of the booklet is 2 older people I'd say in their late 80's sitting on a park bench, I wouldn't think they would mind living with an ICD at that stage of their lives, but for me at 25 is a bit of a reality shock altogether". Kyle

Sofia had a similar experience claiming she felt it wasn't good enough that she had to use Google to get information.

"I know you never can have too much information about anything, to start googling stuff after you have the operation done, I don't think it's good enough" Sofia.

A sense of isolation was experienced following discharge.

"I was a fit and an active 38-year old before this. On discharge I was spoken to by the Nurse, I was given a home monitor which I really didn't fully understand. I was given some literature and information and told if something happens with the I.C.D. or you get a shock you do X, Y & Z. I was discharged and I travelled from Dublin back to home in the country that day and I would probably say by the time I got to the midlands I actually felt very isolated. I felt I was living in the country very far away from a hospital; it was just a very scary experience really. The support was not great for a younger person going home with an I.C.D" Roisin.

The long QT syndrome page was recognised as a helpful site to access information and support.

"I got a lot of answers and support on different medications that have been added to the list of drugs to avoid from the long QT page. I think everyone with long QT should be told about the available apps, and then it is everyone's responsibility to get the app" Sofia.

The information was deemed as conflicting by participants.

"The information from the healthcare professional was conflicting; initially they told me I would lead a perfectly normal life, next I was

told I would never play sport again. This information for a 25year old was devastating. I think Doctors are cautious about the advice they give to patients” Kyle.

Those attending the specialist unit in Dublin had a positive experience and felt they had everything explained to them.

“They explained everything to me about the device, how it functioned and what to expect. They were very good. The whole thing was so efficient a great service. Everything is on time as well when you go for the check-ups” Colette.

6.2.4 Summary of the Theme ‘Being Supported and Being Informed’

From a Heideggerian perspective, this theme focuses on participants’ sense of being supported and informed. Heidegger's tenets of 'being with' 'being with others' and 'care' are reflected in this theme. Participants emphasise the value they place on being supported and informed revealing the meaning and care they place on these ideals. In revealing the importance of these ideals, participants expose what they care about which in this instance is being supported and informed during their initial recovery and adaptation to living with an ICD.

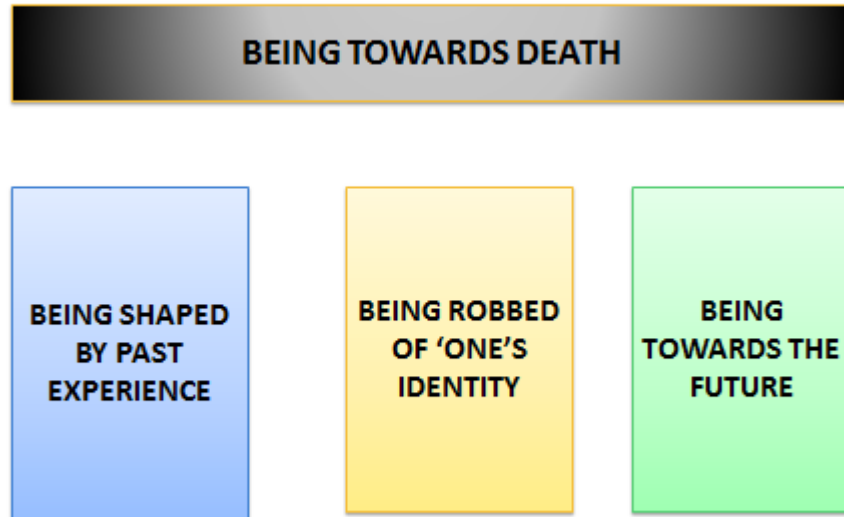
Participants placed particular meaning on 'being with' others in terms of supports received from firstly family and loved ones, and secondly services. From their accounts, it is evident that meaning is inherent with the emphasise participants placed on being with others who provide a supportive, informative context shaping their lived experience of adapting to and living with their device. Participants welcomed whatever support they received from family and friends. This support helped participants cope during a particularly vulnerable period of their lives when they experienced uncertainty during their current existence and moving to the future. Some felt isolated and alone with little support, no access to a support group and limited information. As time advanced participants’ dependency appeared to subside but was prevalent at that particular time. In keeping with Heidegger, things and their purpose are shaped by the context of time. For the

participants in this study temporality shaped the conscious transition of participants' adaptation to living with an ICD. Others revealed that they attended a support group with little benefit. Many were pleased with the support they received from health care providers, but a number alluded to the need for greater medical and specialised nursing support. Many expressed dissatisfactions with being referred to Dublin stating everything was in Dublin which was too far to travel. This contributed to additional stress and anxiety.

Being supported and informed was particularly challenging for participants in the early days' post insertion but also assisted many to regain their independence, to live each day as they had done so previously moving towards the future without the fear of death. The following section will address the theme 'being towards death'.

6.3 Being towards Death

Figure 6.3 Thematic Representation of Being towards Death



The theme “being towards death” reveals participants’ experience of having a cardiac arrest or living with the fear of having an arrest or of dying. This key theme incorporates the subthemes of ‘being shaped by past experience’, ‘being robbed of one’s identity’ and ‘being towards the future’.

This experience they recalled from their past remained with them in the present and reminded them of what could present in the future. The following section addresses participants’ experiences of being shaped by their past experience.

6.3.1 Being Shaped by Past Experience

This sub-theme revealed participants’ sense of being influenced by past events which affected their ability to function in the initial period following implantation.

Many participants revealed the impact a seizure had on their life, and for many, this was the first step of their journey to being diagnosed with sudden heart disease. A number of participants who had experienced a seizure revealed that initially they had been diagnosed with epilepsy. A few participants did not receive a diagnosis, and this was worrying. Participants

found the experience of having a seizure, getting a shock from the device, and being resuscitated a life-changing experience. Some participants relayed the experience of having a cardiac arrest or an occasion when their device was activated and how being resuscitated affected both themselves and their families. The uncertainty surrounding the device activating or not being activated during activities was an additional worry. A number referred to a near-death experience. One participant revealed feeling embarrassed that his device was activated during sexual activity. A number of participants referred to their experience of not been taken seriously because they had not had a previous cardiac arrest. Those who did have a cardiac arrest did not want to experience this again and did not wish to put their family through this again. They had memories of their cardiac arrest and one participant expressed that she never wanted to put their husband through the ordeal of being resuscitated again. Those who had never experienced a shock from their device had a more accepting attitude. However, some participants felt they were treated differently by health care professionals than those who had a cardiac arrest. They felt that those individuals who had had a cardiac arrest had received better support. Many of the participants discussed their family members that died from sudden cardiac death. One participant expressed being heartbroken over her daughter's similar diagnosis of long QT syndrome and was considered too young to have an ICD at present. Roisin was aware of how her cardiac arrest impacted on her family and revealed that she never wanted to put her partner through this again.

“I don't want to put my family through this again. I would hate to put my family back in that position again” Roisin.

Sean expressed feeling embarrassed when it was activated during sexual activity.

“4- 5 months after it was inserted, there's a compromising situation shall we say, this thing activated, and I hadn't a clue what it was. I roared “sorry”. The other person said “fraught”. So, there I was totally and utterly in utter shock at that time. This was the first activation, and it was totally and utterly weird and scary experience.

I was not prepared for it, and as I say what had happened to the situation was an embarrassment more than anything else” Sean.

Many participants spoke of what it felt like to have a cardiac arrest. Nick referred to reliving the experience as he tried to fall asleep.

“It was just like falling asleep. like sinking underneath, the water, sinking down and it was black, and then bang, it felt like you were underneath the water for a long time, and you got out, you and you were trying to get your breath, you just kept trying to breath” Nick.

Participants also described what the sensation of getting a shock from the device was like, describing it as an electric shock or being kicked by a cow.

“I had just made dinner for us all and I stood up to clear the table and this thing went off, o my God it was frightening. I had a spoon in my hand, and I was looking at the spoon and thinking this spoon must be live from the shock I got. I was told in the hospital it would feel like was kicked by a donkey, but it was like an electric shock, I really have no idea what an electric shock would be like. It was horrible, really horrible; I wouldn't want that to happen again you know” Janette.

“I was told by one Cardiac Nurse at the time that if it activates it is like being kicked by a cow from the inside. I was never kicked by a cow on the outside, never mind the inside, so I didn't know what to expect until it happened and then I knew” Sean.

6.3.2 Being Robbed of Their Identity

The previous sub-theme revealed how a study participant's life was shaped by their past experience. Being robbed of one's identity links closely to past experience and reflects how the past has shaped participants' present and relates to how they view their future. Because of events that occurred in the past, they needed to have an ICD, and this was life-changing. They no longer were the person they had been in the past. They talked about losing control. Many things had changed as a result of the ICD. Being robbed of

one's identity represents a sub-theme with many participants revealing how things had changed in their lives since having an ICD implanted. Changes included being restricted with exercise, being unable to lift, being unable to drive, able to care and provide for their children as they did previously, being socially isolated, having a scar, being restricted with clothing, being unable to return to their original job, having difficulty with travel and being dependant on others; all of which contribute to the feeling of being robbed of their previous identity. These changes were revealed by many participants as a result of the ICD. Participants became aware of the physical symptoms and knew what to avoid and when they needed to adjust. However, a number of participants expressed losing their independence and being dependant on family and friends during the early days' post-insertion. Participants revealed they had difficulties attending to their daily activities such as personal hygiene. Arm movement was restricted; they were unable to physically lift their children. However, when post-surgery healing occurred, physical activities were resumed gradually.

Nini recounted her experience of feeling isolated after she received her ICD; she felt her peers treated her differently and no longer wanted to go out socialising with friends because she was afraid of dying.

“I think the biggest change for me, was the fear of the unknown if it going to happen again, I was afraid of dying. After I got the ICD I definitely did isolate myself I wanted to be at home, and I pushed people away. It was such a shock. I didn't really know how to deal with it. I felt people were thinking “oh that poor girl has a heart condition” because I had this thing and asking me questions what to do if a particular situation arose and I didn't know myself. I didn't like that. I was getting “get well soon cards”. I didn't feel sick”

Nini.

Participants were restricted with the clothing they normally wore. Some referred to as being conscious of the scar. Others referred to how the device/ICD felt physically inside them.

“I am restricted in what clothes I can wear as I am very conscious of the scar (laugh) which again is just an acceptance thing” Jessica.

“I felt it was like a brick sitting here on my chest and every time I got up it felt like extra weight, I found that hard for a few weeks. When I went back to school I couldn’t carry my school bag” Nini.

“The ICD, in the beginning, hurt a good bit. It didn’t allow for me being so young and my skin being tighter, for someone else that’s older and their skin is a bit looser, and you can really see it, but with me, it is actually very protruding on the skin, you can feel the ICD and you can see the whole shape of it and the wires literally at this stage. I suppose sleeping is a major thing with it, even showering like, the whole thing of showering, washing your body, even to touch it I was nearly getting sick, feeling this metal inside me of this new part” Kyle

Another participant also revealed how the ICD impacted on their everyday life. Normal everyday activities became a challenge; she was reliant on other people to help with her children, and this left her feeling out of control.

“The biggest challenges for me were driving initially and then work. However, one of the hardest for me was my youngest daughter was only 3 at the time, I normally would carry her everywhere, I couldn’t carry her anymore, I probably shouldn’t have been carrying her anyway, initially, when I went home first I had to say no I can’t lift you. I had to adjust to that, but imagine if she had have been younger again, it would have definitely been more of a problem” Lilly.

Bonny described the ICD as something that had taken over her body; as a result, she experienced depression at that time feeling she was no longer in control of her own body.

“I felt as though something had taken over my body and was controlling it. This actually caused me to become slightly depressed but what can you do?” Bonny

Participants described how their sleep was disrupted due to both the physical and the psychological symptoms associated with the ICD.

“I felt it uncomfortable to lie on the side that the ICD is on when I was going to sleep. I feel as if I am crushing it. I always would lie on that side, but now I tend to only lie on the other side” Jack.

“I had trouble sleeping, every time I closed my eyes it was the same feeling, I felt I was going unconscious again. I’d wake up with an awful shock, it wasn’t that I was getting a shock, but I could feel as if I was getting a shock. It was just like reliving the same scenario; it just kept playing over every time” Nick.

Jessie discussed the physical discomfort associated with the ICD and was aware of the device on movement especially when she exercised.

“I would find using my arm a bit of arm uncomfortable because I don’t have much muscle there in that area. I can feel the wires, it rubs on my skin a little bit. I am still aware of it at times” Jessie.

A number of participants discussed their experience of travelling abroad for holidays, viewing this as stressful. Airports were particularly challenging, especially when navigating through security with the device. Travelling with young children increased difficulties.

“The whole thing about going through the airport security is stressful, there is such uproar when you get there. I have to carry a defibrillator for my daughter, I cannot go through the scanning device myself because of my device and my daughter cannot go through the scanning device either. Trying to explain to people and they don’t understand, although we both carry cards. I get so anxious” Alyson.

“They weren’t very nice at the airport it was a Sunday evening, and it wasn’t that busy, and we still had to be sent down to another area, such an inconvenience anyway we got through it eventually. It didn’t help my blood pressure,” Maura.

The inconvenience of being unable to drive for a period of 6 weeks to 6 months was emphasised by many and this contributed to further dependence and isolation.

“The fact of not being able to drive because of the seizures for six months and not a bus or local taxi service available and even if you were to get a taxi you couldn’t afford it. I would get a lift home after work. It was awful not being able to drive it felt like they removed my arm never mind put in an ICD box” Sofia.

“I had to take off six weeks driving which I found very hard” Jessie.

“Driving again was a major help to my life” Lilly.

Once again as time advanced, these matters appeared less significant. Their scars disappeared, they were able to drive, and they adjusted to the inconvenience of travel. However initially, this caused considerable distress.

6.3.3 Being Towards the Future

This sub-theme relates to participants’ experience of being towards the future. ‘Being towards the future’ links closely with ‘being robbed of one’s identity’, with both revealing participants’ views of the future. Participants were aware of the impact the ICD had on their lives and faced uncertainty towards their future in relation to career and family, particularly in the early days’ post-insertion. Conflicting views emerged in that a number of participants felt secure and relieved to have the device. These participants had a previous cardiac arrest and appreciated having the device. However, they still experienced anxiety and uncertainty towards their device. Some feared it may not work when needed, while others questioned if they

actually needed it at all as it had never activated since insertion. Participants also revealed concerns related to their future. Some expressed concerns related to the diagnoses of sudden death syndrome which created uncertainty in relation to their future. Awareness of the purpose and function of the ICD caused anxiety for their future.

Adam recalled an event that left him with the feeling he was on borrowed time. But because of the event, he found it was easy to live with the device.

“Funny enough, The ICD doesn’t bother me in the least. I am on borrowed time. My friend said I was putting something in the car one minute and he turned around and I was on the ground. And that is what it has been like for me. So really it’s easy to live with. I just get on with it” Adam.

Mark referred to his experience where he was informed about his condition which was similar to sudden death syndrome and that having the device would be beneficial.

They explained to me that I was better to have it and not need than to need it and not have it, when I asked the Doctor what would happen if I needed it and didn’t have it and he said sudden death syndrome” Mark

Nini expressed concern for her future, a fear having another seizure and being unsure if the device would work effectively if required.

“At the time the doctors did explain you know it’s an ICD and it’s going to help you, it’s like a defibrillator but my fear was, I’m going to have another seizure and this thing is not going to work, it wasn’t really explained properly to me.” Nini.

A number of participants referred to the end of life concerns with their device.

Cassie was concerned about her death and her necessity of having the device removed. She had a vision of being dead and buried and the device shocking her back to life in the grave.

“Well, this is very morbid but when I die I want it taken out. In case I am still alive. Take it out altogether to make sure that it’s gone. I want it stopped. I don’t want it left in, I don’t want the defibrillator to kick in when I am two days dead (laugh). That is the only thing that concerns me. I can’t be buried with this. Don’t put the lid on the coffin until you make sure I am gone (laugh)” Cassie.

Participants revealed their experience of having a cardiac arrest.

Adam discussed his experience of having a cardiac arrest and having been resuscitated back to life, revealing how easy it is to die. But he also voiced concerns in relation to a device’s end of life. He was anxious to know what would happen when he actually died and whether it would continue to deliver a shock.

“I don’t remember anything about what happened, but it is quite easy to Die. One minute here and you don’t even know you’re gone. When I was up at one of my check-ups I asked a question, what would happen If I actually died would this device just keep shocking me until the battery runs out” Adam.

Peadar also expressed a similar view.

“When my heart rate increased, the ICD always gave a shock and brought me back, it was painful, but I never was worried about the end of life” Peadar.

Roisin revealed a longing to get back running; however, in view of her past experience of a cardiac arrest whilst out exercising she was worried about being out alone in the event something happened.

“I’d love to go back running but I am still very cautious. I have got back into doing a bit in the gym. I’d love to go back to run, and I’d love to go back cycling, but I actually feel that if I am in a gym I am

in a controlled area and I can watch my heart rate and I can get off the machine then, whereas if I am out on my own and something happens and there is nobody around even though I know I have the I.C.D. I still am anxious” Roisin.

Many participants were grateful for the device. Martin felt secure because of the device and revealed how grateful he was claiming that it saved and prolonged his life.

“I would say only for it I wouldn’t be living today, and I have got it in 9 years, and it did change my life because it helped to prolong it. The device went off and I think according to what I have been told only for I had this device in that night I would have died. I must be very thankful for it” Martin.

Laura was traumatised with her diagnosis thinking she no longer had a future until her children were diagnosed also with long QT syndrome. This rapidly switched concerns for herself to her children, and the future now was about the children.

“When I was diagnosed with Long QT Syndrome, I was obviously devastated and I thought “oh my God, I am going to die” and there was no future for me. On the day I was leaving the hospital, I was told I was in immaculate condition, but there is a 50:50 chance that your children could have the same gene, so they need to be screened. That was in November, and by February I knew that the 3 of them also had Long QT Syndrome, so then it no longer was about me it was more about them” Laura.

Nini expressed doubt if she actually needed the device when she had never used it and considered having it removed.

“I have never had a shock from it, so I said to the doctor when I got my batteries changed in June, why am I getting my batteries changed if I having been using it? I feel like I have had it in now since I was 16 and I haven’t had to use it. I was thinking about not

getting the batteries changed, maybe I don't need this. But then I thought I suppose it is better to have it in maybe" Nini.

Participants discussed making lifestyle adjustments in order to prolong their life and avoid activating the ICD.

"I Stopped drinking at the same time and changed my lifestyle"
Nick.

Reflecting on his experience, Jack expressed his aspirations for the future and a desire for technology to improve, suggesting a warning alarm could go off prior to getting a shock providing time to stop what you are doing, especially if you were out driving.

"The only thing I would like the ICD to have is a built-in sound that would alarm or bleep before receiving a shock. At least you would get a warning. Now I am sure they will come up with something like that in the future, as apparently, it plays a tune when the battery is going down, but that tune should be adapted to a warning sound. Just in the event you could be doing something, like driving and it shocked you" Jack.

From a Heideggerian perspective, it appears participants' present, past and future are closely intertwined with their experience of transition and adaptation to living with an ICD. In the immediate early period participants' adaptation appears to have been shaped by their present situation of now having an ICD and undergoing a transitional process of acceptance with regards to the changes needed to move from their past existence without the device to now accepting living with an ICD device. As the adaptation process continues participants revealed a sense of future directionality in firstly accepting the change they had undergone and now in looking forward in terms of adapting and living with an ICD as part of their ongoing everyday existence

6.3.4 Summary of the Theme 'Being Towards Death'

The theme 'being towards death' reveals how participants questioned their

existence within the subthemes of 'being shaped by past experience', 'being robbed of one's identity' and 'being towards the future'. From a Heideggerian perspective, this focuses on the participant's sense of 'being towards death'. Heidegger's tenets 'ready-to-hand', 'unready-to-hand', 'being towards death', and 'being towards the end', is reflected in the theme. As participants recalled their experience, it became evident that the events of the past were obstructing their ability to function appropriately in the present and preventing them from visualising their future.

Participants revealed that the ICD impacted physically as well as socially in their lives. The previous 'ready-to-hand' life familiar to participants had disappeared and became 'unready-to-hand'. Participants described these past events and the effect they had on themselves and their families. Many had led fit and healthy lives prior to getting their ICD. Suddenly everything had changed; they lost their independence, and they were no longer the same person that they had been previously. They felt they had lost control of their lives. They looked different, they felt different, and they acted differently. They described being unable to conduct simple basic tasks. Younger female participants were conscious of the scar and commented on being restricted by clothing. Participants' biggest disruptions were being unable to drive, which disrupted their home lives. They felt as if they had lost their identity. A number of participants revealed not being able to return to their original job which cast doubt over their future; however, a number did to return to their previous employment.

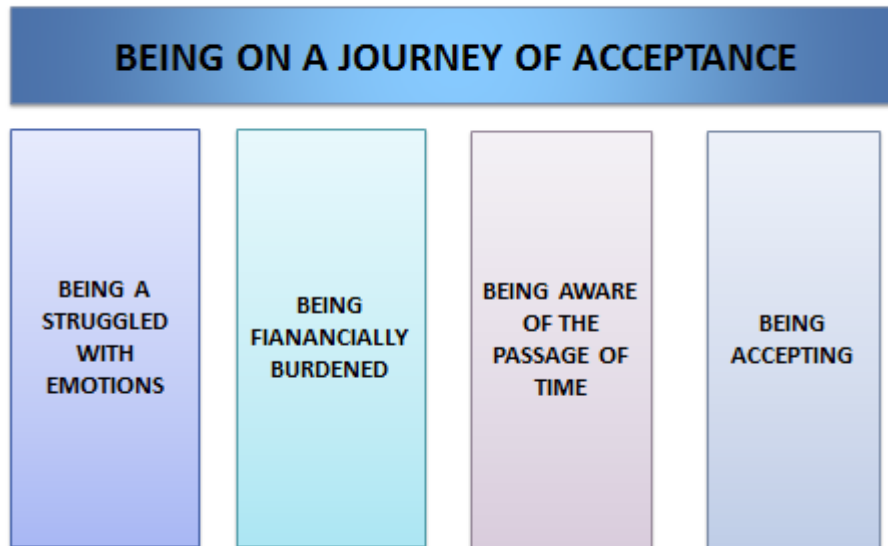
The sense of 'being towards the end' was referred to by a number of participants in their views concerning their death. Some were curious about what would happen when they died while others expressed concerns about having their device removed. Other participants were unconcerned and never thought about their death.

Particular emphasis was placed on 'being towards death' in participants' experience of having a cardiac arrest. It was evident from their accounts that the experience caused considerable distress and impacted significantly

on their lives. Many were afraid and unsure of how much to exercise, fearing they might activate the device. The near-death experience left participants with concerns and uncertainties for the future. An uneasy feeling of death being on the horizon remained a constant reminder. Only when participants were able to understand and make sense of the reality of their experience could they move forward towards the future. These themes reflect the participants' views relative to being. Being able to accept was a challenge that required the support of others, and this had implications for their future. The following theme addresses their journey of acceptance.

6.4 Being on a Journey of Acceptance

Figure 6.4 Thematic Representation of Being on a Journey of Acceptance



‘Being on a journey of acceptance’, represents a key theme in this study. Participants initially recalled conflicting emotions ranging from being shocked, scared, fear of the unknown, exhaustion, being nervous and anxious. A number were glad to have the device and be alive. They referred to the need for “time to get their head around it” in order to learn to live a normal life again. Acceptance was difficult and took time. But eventually, they developed coping mechanisms to help them adapt and adjust their lives so they were able to move on and live as normal a life as they could with the ICD. Roisin described her initial experience.

“Physically, I was sore, I was tired, I was exhausted, I suppose, you had to adapt your life to it really until you got your own head around it, in order could get back to normal living again” Roisin

Nick gave an account of being very anxious and suffering panic attacks which continued until he understood the functions of the device.

“I just remember that I was very anxious since having my previous experience. but once I realized what the device was for, I became

more accepting of having it. I began to embrace it more after that. I had awful anxiety and panic attacks when I was in the hospital”

Nick

Another participant referred to being nervous and anxious with a fear of the unknown.

“When you start doing something, but you are so nervous and so anxious you feel you can’t do it. I remember at the beginning that was what it was like. I can’t do this, I just can’t. I couldn’t feel confident about doing it knowing that it could go off anytime” Lilly

Bonny expressed concerns and fears in relation to basic everyday activities such as having a shower or exercising.

“I didn’t really feel like going out. I had to be careful. I wasn’t even going in an electric shower as I thought I was going to get an electric shock, which was over-exaggerated, but I got used to it. I realised that there isn’t really much you can’t do except lifting heavy weights, but gradually you get used to it which is not a bad thing”
Bonny.

Fears and uncertainty were voiced by many participants about what they could do and not do. They also revealed being thankful for being grateful and being reassured. These conflicting emotions caused considerable stress. Participants were afraid of overexerting themselves and activating the device. They expressed fears of dying. Some had relatives who had died, which enhanced their fears. Others revealed that their personality type contributed to their response but learned to eventually overcome this.

“I am a born worrier. Well, I worry more about people at home than I do about myself and other things too, I used to worry a lot, but I said to myself, what’s the point” Maureen.

A number of participants, both male and female, revealed their depression as a result of needing an ICD. Sean discussed being admitted to the

psychiatric unit and others talked about the need to attend counselling for support.

“I was actually admitted to the Psychiatric Unit here for a brief period, but with the help of counselling, I found this brilliant, having someone to talk with and helped me work through the issues” Sean.

Many participants described how they felt fortunate to be one of those people that lived to get an ICD, but they also felt psychologically fragile.

“I suppose I am very fortunate to be one of those people that has lived to get an I.C.D. put in, but I just think that when something like that happens the emphasis is on keeping you alive giving you the best outcome, but then I suppose from a psychological perspective that is not the case. I think physically you recover but psychologically you are not good. Physically you are not going to recover until you get the psychological state right and I think that is probably, all about education more than anything and that is definitely lacking” Roisin.

Many participants tried to remain positive during their recovery. The feelings summarised by one participant (Sandy) is echoed by many in relation to dealing with their experience.

“You know, there is a lot of things to deal with, no money coming in, your head starts going, but you realise then that your health is more important than anything else and you know if you haven’t got your health you have no life,” Sandy.

As outlined earlier, these conflicting emotions were prevalent particularly during the early stages following implant. However, as time advanced, acceptance was relayed by participants in the recounting of their experience.

6.4.1 Being Financially Burdened

Many participants revealed how they were financially burdened, and this had significant economic implications. Participants were unable to return to work for a period that concerned them. In addition, being unable to drive,

and having to pay for taxis increased the financial drain on resources. This appeared to affect younger individuals in employment more than older individuals who had retired. One participant was living illegally in America and had no health insurance had a cardiac arrest and needed an ICD to save his life. Another participant, a lorry driver lost his HGV licence following the ICD implant and could no longer drive lorries. He described how he lost his livelihood which caused him added distress and concern.

“I suppose initially it was kind of like not knowing what I could do or what I could get back to job-wise, you become quite worried financially, it was very much the unknown at the beginning, there wasn't really much information. The biggest adaption was I lost my HGV licence. I didn't realise this would happen, the Doctor came to tell me before I left the hospital that I would lose my lorry licence because I had an ICD fitted. That was a bigger shock I think than being told I was going to have an ICD fitted because that was my livelihood gone. I thought then oh I can't drive lorries, I'm not qualified to do anything else, what am I going to do?” Michael.

For a number of participants, financial worries contributed to feelings of social isolation. Transport was required for school runs and GP appointments, but they were restricted from driving so their dependence on family and friends increased. In addition, they had to pay for taxis which led to additional financial worries. This contributed to added anxiety and insecurity on top of other stresses. Sofia revealed that financial support would have been helpful because she was now unable to work and living in a rural environment requiring taxis to attend appointments due to the lack of available public transport.

“It was hard living in Donegal with so little support and not mobile with no financial support. I understand that nobody wants to take sick but it is a genetic disorder so I think there should be a bit of financial support if you are living in a rural area. I think the nurse should call out to see you, you still had to attend the GP surgery to get your wound checked and not being allowed to drive is difficult. I was lucky we have no mortgage but if someone had a mortgage and

had to take so much time off work and pay for transport it would be a problem” Sofia.

Younger participants paying a mortgage with young families felt the effects more so than those that were retired with no dependents.

“We were paying for our house, we had three kids. Our mortgage is 800euro. I couldn’t work and we were down 200 euro a week. My husband had to take on a second job” Alyson.

Others talked about the expense and inconvenience of travelling to a Dublin hospital in comparison to travelling to a local hospital.

“I had to get the train up to Dublin, get a taxi from the station to the hospital, then go in pay €60, come back out, get a taxi, get a train. And now, I can come up to my local general hospital and get it all done for nothing” Eddie.

Participants also voiced concerns in relation to financial worries following implantation. Financial worries particularly impacted participants living in rural locations, as a result of being unable to drive and work. Over time, these concerns were less pertinent but highlighted as a significant aspect of their earlier experience.

6.5.2 Being Aware of the Passage of Time

This sub-theme reveals participants' experience concerning the passage of time. The previous sub-theme of 'being a struggle with emotions' is closely connected with this sub-theme as with the passage of time participants began to improve psychologically.

Participants revealed how they struggled with many emotions during the early period post-insertion. Those who had their device implanted for a number of years revealed that over time they were able to adapt their lifestyle and become more accepting. The time for acceptance varied for individuals; one revealed it took six months while for another it took 3 – 4 years to come to terms with the device. Some avoided looking at it, pretending it was not there. There was an element of denial associated with it.

"I would say it took 3 – 4 years before it becomes part of you. You learn to accept it, before that you were always conscious of it, even coming out of the shower, you'd try to avoid mirrors so you wouldn't see it. You come out of the shower, and you are drying, and you don't dry that side of your body, you are avoiding it. Trying to fool yourself there was nothing there, in your own mind, and at the same time you know it's there" Nini.

Many participants understood the device's purpose and seemed grateful and relieved to have it, viewing it as a backup plan. This appeared more evident in those individuals who had never had a shock or a cardiac arrest. Participants revealed how it was difficult in the beginning but through time it became easier.

"I have it now and am competent with it, and actually glad that it's there. If I had known back 9 years ago what I know now I would be a different person. Time does help you come to terms with it probably, they say time is a healer and in this case, it's true, it is a very positive thing for me" Sean.

For Alyson, the length of time that it took for the scar to heal and for her to become less aware of the ICD was 6 months.

“I would say I was aware of it for about six months and would have felt it moving. But you get on with living once it beds into the tissues. I would never notice it now knows. You feel it and at the beginning especially if wearing something tight, as it was coming into summer and I would be wearing a vest top or something like that, my scar is very neat, as you can see yourself it's very faded it's a great neat job” Alyson.

During the early stage of recovery, participants referred to wanting everything to happen quickly, but they soon recognised that time played a crucial role in their recovery. It was necessary to allow time to accept.

“I just wanted everything to happen quickly, but I just realised I had to sit back and give myself time to accept it, to learn to live with it and to get better after the operation” Bonny.

Time, played a significant role in participants' experience of learning to understand, adjust, accept and live with the device. There were several hurdles to overcome before reaching this point.

6.4.3 Being Accepting

The previous theme refers to the passage of time and how it relates to participants' experience. This subtheme reveals participants' experience in relation to being accepting of their ICD. Both themes are closely interlinked. Acceptance for most participants was an emotional journey that involved time. Each individual's experience was unique. Many found adapting to the ICD a challenge whilst they appreciated that they had received a second chance at life, they found it difficult at times to focus on the positive aspect associated with the device. Each participant had their own issues to deal with and developed their own coping strategies over time. Regardless of the indication for insertion, acceptance was key. Some were more accepting than others and felt secure because of it. This was particularly evident in those who had experienced a cardiac arrest. Those who had not experienced a cardiac arrest struggled to understand the need for insertion and reach

acceptance. Being able to arrive at the point of acceptance was the final stage of the journey for participants.

Participants revealed how they had to learn to accept. Being told you are unable to return to the original job was difficult to deal with. They questioned their worth as an individual.

“I was in a bad place for a while. It impacted on my life to a certain extent, I couldn’t drive at the beginning, and then when I was told that it would be better not to go back to doing the job that I was doing as it was a heavy job. Accepting that was a big thing. I thought, right if I can’t do my job, I can drive, what good am I”
Bonny.

Participants revealed how they developed a coping mechanism like sitting down and relaxing to prevent the ICD from activating.

“Sometimes I suffer from shortness of breath or feel my heart beating funny, you expect the device to kick in, and you sit down and relax. When you think it is going to activate, you do get a feeling coming near to activation” Sean.

Jack felt better after getting the ICD, revealing that he slept much better and felt more secure.

“Well, overall, my experience after I got it was I felt a bit more secure with it. I actually felt I could sleep better. I was having arrhythmias and I could feel them at night in bed and after I knew I had the ICD I knew that was going to sort that, nothing was going to happen to me such as having some life-threatening event,” Jack.

Maria referred to having the confidence to live with the ICD and recognised that they may not be alive if they did not have the device in situ.

“A lot of the time I don’t know that it is there. It disappears, then maybe some night I turn over and this thing is sticking out in your chest, but 90% of the time I don’t know it is there, so it’s all right, as

long as it's there. I really feel I wouldn't have the confidence to live as I'm living if I didn't have it, Thank God for it and VHI" Maria.

Jenny revealed that she didn't think much about the device and actually felt more secure knowing that it was there if needed.

"The only difference is you feel may be more secure knowing that it's there and it may be useful someday. To tell you the truth I don't think about it, I mean it's not a problem for me. I feel very secure that I have it" Jenny.

Nick revealed that he never thought too much about the device. He just viewed it as something that was present, until he had a cardiac arrest and received a shock from it. He was aware he needed it.

"I am aware of it. But I never viewed it as a bad thing, I just viewed it as a thing at the beginning, it was just this thing that they said I needed to get in and I never really thought about it, I suppose I just didn't realize that I needed it, that I really needed it until I needed it. It took a cardiac arrest. But I know now that it is a great thing to have" Nick.

Eventually, participants revealed that they had come to terms with the ICD, accepting it and learning to live with it, and now viewing it as a security blanket. Participants revealed they felt more secure knowing they had this device.

"I don't look at it as there is something wrong with me. I view it as a security blanket more than anything it is there if I need it. Knowing this is a source of great support. Hopefully, I won't ever need it, but I know it is there if I do ever need it. If I had a shock I might feel completely different. Maybe that's the wrong way to look at it but that's my way. Yes, that's my experience" Carla.

Older participants viewed their experience differently; they appeared to have developed a more accepting attitude, this was definitely evident in those that were retired.

“You have to take what God sends you and you have to get on with it and that’s it. What more can I do, there’s nobody else that can solve the problem. I wasn’t working. I was retired. You think that once you retire you could enjoy a bit of life, but you have all these problems that keep popping up and that’s it” Sarah.

“Most of the time I don’t even know it’s there. I have never got a shock from it. It is only when you go for a shower that you see it. It’s not holding me back in any way if anything it’s a help, it’s doing its job and what more can I ask. There is a thing beside my bed, that records when the heart speeds up, they can view it in Dublin. It’s great having someone keeping an eye on you” Harry.

Participants revealed that acceptance was the major factor in their road to recovery.

“Acceptance was a big thing, accepting, that I needed it and then I finally accepted it” Bonny.

“It was just accepting that there was an issue even though I knew deep down there was. I couldn’t understand a box in you. I would try to be quite positive, I realise that I have the chance that my mum didn’t have for example, and I am lucky to get it in before the stage my sister that had a stroke was at. I can have sympathy days as well (laugh). I am allowed them but they are few and far between I try to stay positives and accept I am lucky, so that’s the main thing” Jessica.

Participants eventually learned to accept, and while daily reminders persisted, they lessened with time.

6.4.4 Summary of the Theme Being on a Journey of Acceptance

The theme of ‘being on a journey of acceptance’ from a Heideggerian perspective reflects Heidegger’s tenets of ‘ready-to-hand’, ‘authenticity’, ‘being in the world’, ‘angst’, ‘temporal’, ‘resoluteness’ and ‘clearing’. Learning

to accept their ICD was challenging for most in the initial phase. Participants experienced fears, concerns, anxieties and uncertainties related to 'being in the world', with this object which appeared alien to them. The 'ready-to-hand' world they had previously been accustomed had become 'unready-to-hand' and no longer functioned as it had done previously. 'Angst' or anxiety remained present for a considerable period of time causing what many participants referred to as "not in control". Participants revealed how they experienced a cocktail of conflicting emotions before they could eventually arrive at acceptance. Many endured sleepless nights worrying and fearing death. They worried about losing their livelihood and not having any income. As reflected in Heidegger's tenet 'temporal', time assisted their ability to accept.

Participants revealed their social context and what is of consequence and influenced them in their everyday lives. Some of these social structures shaping their existence included financial challenges, loss of earnings, loss of being able to drive and mental health challenges linked with the adaptation process.

From a Heideggerian perspective what was revealed was the structural context shaping participants lives before and after the device was inserted. It also reveals a distinct change in participants 'care structure' which is what matters to them shaped by the temporality of the passage of time. What participants reveal is a reprioritisation of their personal values and beliefs in accepting and learning to live with an ICD.

Participants recognised how important time was in relation to their experience, not alone the period of time they were now living in, but how their life improved with the passage of time. Within the study older participants appeared more accepting and less anxious than younger participants. Younger participants focused on the hereditary factors associated with their diagnosis and how it would affect their children. Those who were still working and had young children dependant on them and needed to drive were restricted. Concerns were voiced in relation to being

unable to fulfil day to day household tasks. Older participants retired with no children dependant on them were less concerned with driving and more focused on remaining independent. They appeared to focus on their underlying cardiac conditions and complex comorbidities which took precedence over their ICD. They appeared less concerned with travel and body image than the younger participants. 'Angst' anxiety and fear appeared from the participant's account to threaten their ability to regain control.

Participants described how they developed specific strategies to assist them to deal with these emotions. Some took a more positive attitude claiming it changed their life for the better. They felt secure knowing the device was there. Participants were grateful that their device was there should they need it. A number of participants revealed that they no longer think about the device being present but were aware that it could be useful someday. They were aware that the passage of time assisted in easing their journey. With time they learned to accept it. Eventually, participants expressed how they began to view things differently, referred to by Heidegger as a 'clearing' (Lichtung). Their 'being in the world' becomes illuminated, and their focus becomes more about the outcome rather than the object. Participants recognised their available choices; they either could accept or reject, and by choosing to accept they regained ownership of their 'authentic' self. It is evident from this study that participants struggled to deal with a number of challenging issues throughout their journey. Financial insecurity and conflicting emotions led to fear anxiety and uncertainty. Time was emphasised as assisting them to regain control and eventual acceptance. This became easier with the passage of time. Heidegger refers to this as resoluteness, allowing one to be summoned out of one's lostness. Enabling one to reach the point of acceptance and see beyond the horizon.

6.5 Conclusions of Summaries

Acceptance is a major factor in living with an ICD. In order to arrive at the point of acceptance, individuals had to experience a turbulent journey. Being financially burdened robbed them of their identity causing a struggle with a number of conflicting emotions. The events of the past left a scar leading to uncertainty and apprehension about the future however gratitude and appreciation for the present remained. Future directionality linked with adaptation, acceptance and moving forward in a 'new' existence living with an ICD device resonates with Heidegger's tenet of temporality living in our present, shaped by our past and focused on our future. Through the passage of time acceptance began to emerge from beyond the horizon. This would not have become possible without the invaluable support of family friends and a number of health care professionals. As the fear of death began to subside a new dawn emerged and the ICD no longer was viewed as the enemy.

The themes and sub-themes which emerged from this study revealed how the experience impacted physically, socially, psychologically and financially on participants. Participants' experiences varied depending on their age and their stage in life, but many voiced similar concerns. Conflicting views emerged amongst participants ranging from positive to negative. The themes and sub-themes revealed by the participants and interpreted by the researcher in this chapter provide an insight into the lives of those individuals living with an ICD. Each participant experience was unique and personal, and although many shared similar experiences, some experiences were elite. These themes and sub-themes are interlinked and reveal the stages experienced before eventually being in a position to come to terms and gain acceptance of the ICD.

The findings of this study clearly illuminate participants' experience throughout their journey outlining the obstacles and concerns they encountered on route to acceptance.

In seeking to make sense of the experience I drew on Heidegger's philosophical work to demonstrate the importance of how Heidegger's tenet 'temporal' played an important role in participants' experience relating to information and support immediately post-discharge. With time, their anxiety subsided, acceptance emerged and living became easier. The importance of Time and 'Being with other's' helped free them from 'Angst' assisted them to embrace the 'ready-to-hand' to reclaim their 'Authentic' self, freeing them from their fear of 'Being toward Death'

The following chapter will provide an in-depth discussion of the study's findings in the context of the ICD's effect on participants' lived experience with reference to relevant empirical and philosophical literature. ICD is an embodied experience, affecting all four lifeworlds (lived time, lived space, lived body and lived relations) (van Manen, 1990), and these four existential tenets have been adopted in framing the discussion to follow.

Chapter Seven: Discussion of the Findings

7.1 Introduction

The purpose of this hermeneutical phenomenological study was to reveal the experience of living with an implantable defibrillator. The key finding centres on the ICD's effect on participants' lived experience. In the context of Heidegger's philosophical focus, the key themes revealed were 'Being Supported and Informed' 'Being Towards Death' and 'Being on a Journey of Acceptance'. As a whole, these themes reveal the phenomenon and meaning of 'living with an ICD' for this study's participants. Collectively the themes reveal a complex convoluted lived experience shaped by the temporal journey of receiving a diagnosis, undergoing the procedure of ICD insertion and the lifeworld of the participants' journey of transition, adaptation and acceptance shaping their future directionality of living an everyday existence with an ICD device.

To discuss this complex convoluted lived experience van Manen's four lifeworlds (van Manen, 1990) has been chosen as this approach afforded an opportunity to discuss the complexity of this study's findings in a coherent manner. van Manen's lifeworlds mirror those expressed by Heidegger and others and capture the '*intertwined*' philosophical perspectives on the lifeworld.

Using this approach facilitates discussion of the lived experience revealed in this study's findings from the perspective of lived time, lived space, lived body and lived relations.

The findings have revealed that there is a need for improvement concerning access to services, information and specialist support, particularly for individuals who experienced a cardiac arrest and reside in rural areas. This new knowledge can help inform the current body of evidence, healthcare professionals, policymakers when planning future care and ultimately inform practice.

In keeping with Heidegger's philosophy, my interpretation of the participants' interpretation revealed that the implanted ICD was an 'alien' within, a constant reminder of participants' mortality. They struggled with adaptation to the 'alien' and existed with a heightened awareness of past events which robbed them of their identity, threatened their mortality and elicited fears and apprehension about their future. Participants were consciously aware of the device's role and presence. Every decision relating to their day to day existence was made in the context of an awareness of the device. No decision could be made in isolation to the device. Social connections and support helped to live with the device. Whilst many of these challenges and fears subsided with time, it is important to acknowledge that they do exist, impacting on all aspects of each individual's life, physically, socially and psychologically.

As living with an ICD is an embodied experience, all lifeworlds were affected (lived time, lived space, lived body and lived relations) (van Manen, 1990). Therefore, van Manen's (1990) existential tenets have been adopted in framing the discussion to follow from an empirical and philosophical stance

7.2 Lived Body

Being an ICD recipient was *being robbed of identity*. The ICD implant, an 'alien' within, caused many new physical changes and sensations such as pain, lack of sleep, body image and occasional shocks. The 'alien' remains invisible to others and interferes with the person's routine daily activities, such as caring for their children, going to the gym, driving, travelling abroad and sleeping. Therefore, concerns centre on lifestyle limitations and a loss of identity prevail.

The intended purpose of this 'alien' device symbolised death for some participants and life for others. Many participants who had experienced a cardiac arrest were still haunted by this past event. However, those who had not experienced a cardiac arrest viewed the ICD as life-extending. Both male and female participants referred to vivid dreams, nightmares and

disrupted sleep patterns, resulting in tiredness and exhaustion throughout the day. However, it has been reported that certain predictors are associated with poor quality sleep with an ICD, such as female gender, pain, anxiety and depression (Pederson et al., 2009). Moreover, symptoms can differ amongst genders; with women experiencing more pain and sleep difficulties following implantation compared to men (Smith et al., 2006). Other studies too also report on the sleep disturbances following ICD implant, mainly related to fear of ICD discharges (Berg et al., 2012; Gallagher et al., 2014). In addition, the Canadian Implantable Defibrillator (CID) study found that this fear was greater in those who had a previous defibrillator shock (Irvine et al., 2002). Physical sensations and pain were also mentioned by some participants. The pain occurred mainly in the initial stage following implantation, but also on sudden movement or occasions when their child or grandchild accidentally hit against it. Appropriate advice and education from health care professionals might assist in targeting these types of adjustments leading to an improved quality of life. Adequate pain management is vital to prevent sleep problems among ICD recipients (Pederson et al., 2009).

These physical sensations acted as reminders of the ICD's presence, and participants' new identity. Moreover, an objectified vision of self occurs when one's appearance is less than the desired appearance leading to negative emotions and anxiety (Impett, Daubenmier and Hirschman, 2006). Some participants voiced concerns relating to their body image and how others perceived them. They chose to wear clothes concealing the scar. If the scar was hidden no one would know that they were different. This was particularly prevalent in younger females. One young participant was offered the choice of having the device implanted under her arm which she accepted; it was less visible than on her chest causing less attention. A conversation around the implantation site might alleviate concerns related to body image. While similar findings regarding the implantation site were not found in the literature, others have reported on the ICD's effect on body image (Vazquez et al., 2008; McDonough, 2009; Fydensberg et al., 2018; Pasyar et al., 2017). Different changes in body image have been reported

(Pasyar et al., 2017), and visibility of the scar can result in feelings of discomfort and embarrassment which impacts on social lives (Fydensberg et al., 2018). Feeling uncomfortable swimming and choosing to wear clothing that did not reveal the scar is also an aspect of living with an ICD (McDonough, 2009).

Those living with an ICD experience both physical and psychological awareness of its presence (Fydensberg et al, 2018). From a Heideggerian (1962/2001) stance, the body and mind are viewed as inseparable. When the body is free from illness it functions quietly in the background. However, when illness strikes, the physical body changes affecting the individual's perceptions of their body and world. Dahlberg (2019) postulates that the body shapes the individual's perspective of their world. The body is a biological being consisting of several structures that perform precise functions important for everyday existence (Rettner, 2016), and is the reason that we have a world in the first instance (Dahlberg, 2019). A healthy individual can freely instruct the movement of the body, referred to by Merleau-Ponty as 'a spontaneous and free spatial thought' (Canas, 2019 P 206). However, in contrast, the unhealthy body must invest in preparation to undertake an action. Participants within this study appeared to mourn the loss of their functioning body, conscious of its sense of fragility revealing from a Heideggerian stance an aspect of their core care structure that exposed the importance and need for support. This new understanding highlights the importance of providing psychological support to those living with an ICD so they can adapt to what they perceive as living with an alien that enables their body to function and remain fully operational.

The participants in this study remained physically able to mobilise, but the ICD caused restrictions. Embodiment is a response and awareness of sensations in the body (Impett, Daubenmier and Hirschman, 2006), and is fundamentally twofold, subject and object combined, lived but also material (Wehrle, 2019). Merleau-Ponty in his writings refers to an understanding the body reaches through perception (Canas, 2019; Hoel and Carusi, 2018; Priest, 2000). Embodied perception allows the visible, spatial, touchable and

material world to come to life (Moran, 2018). van Manen (2007) proposes that we might discover our knowing by how we perform and what we can do, relating to our world and others in our embodied being within the scope of temporality. The temporal aspect of embodiment is encapsulated in both the present and habitual body which possesses a distinctive array of abilities (Kelly, 2014). For the study participants, care of the body was a habit, something that came naturally to them without thinking. Loss of identity was associated with the restrictions they experienced in performing day to day activities of daily living. Because of the ICD, the skills which previously had come naturally now brought fear and anxiety. Losing some of these activities is compared by Zayac and Finch (2009) to losing aspects of personal identity. In addition, loss of skills is often associated with advancing age, and this might account for older participants expressing fewer concerns about living with the ICD. A review of adults living with ICDs found that older people with ICDs may be more accepting of physical limitations due to ageing whereas younger people are inhibited in driving, working, sports and physical activities (Tagney, 2010).

In *being towards death*, study participants worried about activation of the ICD. Many had already experienced sudden and unexpected activation of their ICD and there was a constant risk of arrhythmia which could be potentially fatal. Living with an ICD brings concerns about being dependent on a battery for heart function (Pasyar et al., 2017), subsequent physical and psychological effects, and apprehension when planning activities. Some participants living in rural areas also felt they were disadvantaged residing several miles from their local hospital. Many of the participants lived between 50 and 60 kilometres from their closest hospital. Several counties in Ireland are geographically broad resulting in a considerable distance to attend the nearest hospital. Lack of public transport is an additional factor. Many participants did not have access to public transport and did not drive. If they urgently required an ambulance, they feared the ambulance personnel would have difficulty finding their house (Eircode/Postcodes have since been introduced). A number of participants referred to follow up clinics in Dublin, but this involved considerable planning, financial burden

and hours travelling for an appointment that may have only lasted a few minutes. Urban-rural health disparities are well known and one main factor for this is differences in access to health care (Ebherhardt and Pamuk, 2004; Government of Ireland, 2021).

Patients with ICDs are susceptible to mood disorders due to a variety of factors, such as the unpredictability of a shock or the nature of their disease (Oshvandi et al., 2020), and a broad array of psychological disorders can occur ranging from panic attacks to anxiety and depression (Kajanova et al., 2014; Morken et al., 2012). In addition, post-traumatic stress disorder (PTSD) among ICD recipients due to their fear of a shock is widely reported (Habibović Denollet and Pedersen, 2017; Kajanova et al., 2014; Kobayashi et al., 2014; Ladwig et al., 2008; Morken et al., 2014; Sears et al., 2011; Shinga et al., 2013). Patients experiencing multiple ICD shocks report the event as traumatic and feared their life was in danger and they developed PTSD as a result (Sears et al., 2011). This threat to a patient's life and well-being is persistent and permanent (Ladwig et al., 2008). Unlike other survivors of life traumas, ICD recipients are constantly exposed to the threat of future ICD shocks occurring, therefore the fear is valid (Sears et al., 2011). Women who received a shock from the ICD are more prone to anxiety than men irrespective if they receive a shock from the device (Spindler et al., 2009) Spindler et al. (2009) also reported that women experienced greater impaired physical and social functioning, suffering more anxiety and ICD concerns than men.

Thinking about death causes fear of death, affects daily life and causes psychological distress (Asghari and Arabi, 2019). ICD recipients can feel fragile and vulnerable, experiencing loneliness, and thinking that death could come at any time (Garrino et al., 2018). Moreover, in general, studies have revealed low self-esteem and confidence can lead to anxiety affecting prognosis (Ociskova et al., 2013) and have a toxic effect on their mental health (Hing and Russell, 2017). In addition, although shocks are necessary, inappropriate shocks can arise and are painful (Auricchio et al., 2015), and this fear results in ICD recipients restricting their daily activities

for fear of receiving a shock (Mert, Argon and Aslan 2012). However, for some, the ICD is a security blanket due to its lifesaving capabilities (Cornelius, 2015) and those who do not experience a shock from the device report fewer changes in their lifestyle (Mert, Argon and Aslan, 2012). Living in fear of a shock is a real consideration for people living with an ICD as the purpose of this device is to deliver a shock when needed. Participants reacted differently knowing this. Some of those who experienced previous cardiac arrest or those who were informed by the cardiology team of the risk of a life-threatening arrhythmia understood the real threat to their mortality and were grateful for the second chance at life. They recognised the ICD as an insurance policy or security blanket accepting it immediately. However, others suffered guilt for relatives who died prematurely and never got the opportunity to get an ICD. Some were angry and anxious at their initial diagnosis, taking considerably longer to accept; and this was more evident in the younger study participants. Some participants viewed the device as a threat whilst others viewed it as a friend. Perhaps this may be due to a device never activating or due to participants' age. Moran's (2018) writings on phenomenology highlight that existence must be viewed in relation to its temporal and historical components to fully understand why people respond in the manner they do. Regardless, each participant had their own individual thoughts and feelings relating to the device. Psychological assessment and counselling initially and supports put in place depending on identified needs, could assist with alleviating many of these concerns following implant and foster a path to individual recovery. In addition, for those living in remote rural settings, remote monitoring could be used to help with anxiety. Remote monitoring has been developed by many device manufacturers and is now available for online transmission to assess the device functioning (Galli et al., 2019).

Recipients of an ICD in Dickerson's (2002) qualitative study compared the device to a double-edged sword; while they were grateful for it, they also feared it. Emotions alternated between shock, fear and uncertainty, to gratitude and relief. These ranges of emotions have been reported in other studies involving ICD recipients (Abbasi et al., 2016; Garrino et al., 2018; Saito et al., 2012).

Regardless of the lifesaving capacities of an ICD, individuals with this implant will continue to die from non-cardiac related conditions (Fluur et al., 2013). In this study, some participants expressed concerns if the device continued to deliver a shock after their death. Dying from non-cardiac related diseases and fears of how the device could continue to shock (even though it was pointless to do so) have been expressed elsewhere (Flanagan, Carroll and Hamilton, 2010). Unsurprisingly, several studies have recommended conversations with ICD recipients about the deactivation of their device (Beattie, 2013; Hill et al., 2015; Hill et al., 2016; Mooney et al., 2019; Padeletti et al., 2010; Stoevelaar et al., 2020; Tagney, 2007; Templeton, 2015). The European guidelines recommend discussions on the quality of life with all patients before device implant and during disease progression (Priori et al., 2015). Deactivation refers to turning off the shocking button if an individual was approaching the end of life. It is known that arrhythmias can increase near the end of life (Fluur et al., 2013; Mooney et al., 2019), and while guidelines have focused on the end of life to support healthcare professionals to address these concerns (Epstein et al., 2013), further investigation is necessary to understand how patients perceive dying with an ICD (Hill et al., 2016) and how health care practitioners can best advise and support patients at this critical time in relation to deactivation (Hill et al., 2018).

In summary, participants expressed a heightened awareness of their body and the 'alien' within. This loss of functioning contributed to their experience spatially, corporeally, temporally and rationally. This experience resonates closely with Heidegger's notion of 'care' exposing participants' strong sense of their own mortality and their refocusing on their personal

life and shared interactive life with others in their world. Further research may assist in understanding participants' psychological varied reactions to their implant. The need for further exploration regarding how resilience could be supported, built upon or developed may assist healthcare professionals to plan care to help participants adapt to living with their ICD.

7.3 Lived Relations

For the study participants, support from family and friends, appropriate information, and access to follow up support that influenced recovery were important. *Being supported and informed* was particularly important in the early days following hospital discharge. However, while *being with* others was important for many, it posed challenges for others.

Heidegger's reference to '*Being-with*' resonates with van Manen's rationality (lived others). The relational aspects from a Heideggerian stance refer to Being-with; viewing individuals as inseparable therefore Dasein can connect easily to others (Paley, 2014). Participants' reimagined perspective of their 'being in the world' reflected an enhanced sense of their importance of 'being with' others of significance to them. Participants found comfort in the support of others, particularly in the early days post-implant. However, some expressed disappointment in the lack of support from significant family members. *Being-with-others* from a Heideggerian stance acknowledges we are not alone in the world and others contribute to our existence. Our everydayness involves communicating with others regardless of the mode. Support of others for those living with an ICD has been highlighted in other qualitative studies. The support of family and friends can be invaluable in helping those with an ICD cope with daily living (Morken, Severinsson and Karlsen, 2010). Moreover, Ooi et al., (2018) reported on strong social support of family and friends, however, this support can be perceived by some as overprotective (Bolse et al., 2005).

Participants' mixed experiences relating to support received from healthcare services was evident, with differences between rural and urban healthcare support revealed. Those who lived in the city had only ten minutes to travel

to any hospital, whereas for those in rural areas attendance at follow up clinics usually involved many hours of travel. In addition, attendance at their local hospital when complications occurred also involved referral to the tertiary hospital. Furthermore, participants' views on local support groups were also mixed; some welcomed them whilst some had previous negative experiences. Those who attended a cardiac rehabilitation or heart failure support group programme had a positive experience. Mixed experiences of support groups are reported by Bolse et al., (2005) in a qualitative study and attributed to the various ages and heart conditions of people in the group. In addition, participants in another qualitative study revealed their experience of support groups as a venue to complain (Flanagan, Carroll and Hamilton, 2010).

Participants expressed positive support associated with specialist units where they had access to a designated nurse specialist at any time through email contact. ICD recipients in a qualitative study have expressed their trust in healthcare professionals because of their expertise and extensive knowledge (Ooi et al., 2018). However, lack of follow up and regular contact with a healthcare professional proved problematic for some study participants, adding to their uncertainty concerning how much activity was safe. A qualitative study with young ICD recipients (aged 18-40 years) found that they continued to exercise, however, they chose a less strenuous activity to avoid increasing their heart rate despite being active before their implant (McDonough, 2009). In addition, Flemme et al (2011) in their all-male grounded theory study reported that some ICD recipients test their device disregarding the information they were given and choosing to resume playing competitive sports again and increasing their physical activity despite being advised of the risks.

Some expressed satisfaction with the initial information provided by the cardiologist on their need for an ICD. ICD recipients' satisfaction with initial information is widely reported in the research literature (Bolse et al., 2005; Flanagan, Carroll and Hamilton, 2010; Garrino et al., 2018; Mert, Argon and Aslan, 2012; Ooi et al, 2018; Pederson et al., 2017; Zayac and

Finch, 2009). However, many participants were unhappy with the information provided during the initial stages of post-implant. These varied experiences may be attributed to whether the device was implanted after a cardiac arrest or not. Some participants referred to being taken less seriously by healthcare professionals if they had not had a cardiac arrest, but most had their device implanted in an emergency, and they were grateful for the life-saving device and trusted the expertise and judgment of the cardiologist.

Several participants felt that the information provided was inadequate and sought information through internet searches. Although many were aware of the functions of the device, some were unaware and only informed when issues occurred. It is reported in other research studies that ICD recipients live with uncertainty and unanswered questions (Carroll and Arthur, 2010; Carroll, McGillion and Arthur, 2014; Flemme et al., 2005; Flemme et al., 2010; Mauro, 2008a; Mauro, 2008b; Mauro, 2010). In addition, health care professionals' lack of practical information provision has been highlighted by participants in a recent phenomenological study (Garrino et al., 2018). Participants in a Turkish study give the example of a lack of information on how the device operated (Mert, Argon and Aslan, 2012). Others too report mixed experiences from ICD recipients. While participants in a recent study noted ICD recipients' high level of satisfaction with the information received (Pederson et al., 2017), Flanagan, Carroll and Hamilton (2010) reported participants' lack of involvement in their care. Following a survey of ICD recipients (n=263) in the US and Australia, Hammash et al. (2019) conclude that education is crucial and empowering and should be integrated into treatment plans. Other researchers highlight the need for individualised information to target the unique needs of each ICD recipient (Bolse et al., 2005; Zayac and Finch, 2009). Furthermore, the presence of an ICD specialist nurse pre, during, and post ICD implant for practical and emotional support is recommended by Bolse et al., (2005).

The benefit of social capital in the lives of the ICD recipients is evident. Theoretical views on social capital and social support highlight that they may have a buffering effect on psychological distress related to sickness

(Fiorillo and Sabatini, 2011). The presence of family and friends were revealed as positive supports. All participants had a positive experience with their cardiologists and expressed their trust in them. However, many referred to inadequate informational support from health care services. Support from health care professionals varied from centre to centre. Moreover, participants living in remote areas and poor infrastructure presenting a particular social structure negating their agency to access services. This arguably reflected an inequity in service delivery to participants living in remote areas. This inequity echoes what Robinson et al. (2002) argued is the potential benefit or lack of social capital can have on transformative capacity at the individual level. For participants in this study, their lack of access to expert services to exercise their individual capacity toward the transformative processes of self-efficacy and self-determination to effectively live with an ICD was negated.

Furthermore, those whose implant was prophylactic expressed dissatisfaction with information received as they did not have a definitive diagnosis, and this was particularly evident with those not associated with specialist units. This highlights the need for referral or liaison to a specific individual who could respond to participants by phone, text or email and alleviate any concerns. Devoting a particular day in the year to cardiac care, similar to cancer care, could present an opportunity to inform the public of all cardiac conditions and address any misconceptions held by the public. Overall, 'lived relations' was an important element of support in this study, but also exposed several opportunities for change.

7.4 Lived Space

The 'alien' within affected *being towards the future*. For study participants, travelling abroad was referred to as a 'nightmare' due to the extra planning and vigilance required at an airport. Airport security needed to be informed about the device and reminded that ICD recipients could not go through the scanner. Participants also referred to be feeling uncomfortable at airports and being observed by others. Fear of magnetic fields is a real emotion revealed by ICD recipients (Pasyar et al., 2017).

Activation of the ICD was a concern for all participants. In a pilot rehabilitation program, it was found that activation can have practical and financial implications resulting in driving suspensions for a period of up to six months (Frizelle et al., 2004). Driving was equally important for all participants, irrespective of age or gender. Many participants referred to driving restrictions as one of the most difficult issues related to living with an ICD. This was especially so for participants living in rural communities who were dependent on their cars for transport. According to the European Heart Rhythm Association, the driving ban following implantation significantly impacts on the quality of life of recipients and their spouses (Vijgen et al., 2009). The Japanese Heart Rhythm Society's review of the literature and national data highlights that many ICD recipients may be healthy enough to drive, but some can develop syncope and loss of consciousness whilst driving due to ICD activating (Watanabe, Abe and Watanabe, 2017). Risks to the public occur as a result of activation.

Guidelines and recommendations have been proposed to support healthcare professionals to address this issue. However, these guidelines may vary across territories. Based on the American Heart Association (AHA) guidelines, drivers of private vehicles with an ICD implanted for primary prevention are restricted for one week. Drivers of private vehicles implanted for secondary prevention are restricted for six months. Drivers of commercial vehicles are permanently restricted (Kim et al., 2015; Vijgen et al., 2009). The European heart rhythm association (EHRA) are similar to the AHA guidelines. However, the National driver licence service (NDLS) Irish guidelines vary slightly in comparison to the AHA and EHRA, suggesting four-week restrictions for primary prevention. Therefore, adequate education is critical for patients and families concerning driving restrictions as highlighted by the Japanese Heart rhythm Society (Watanabe, Abe and Watanabe, 2017). Risk assessment is also vital to ensure that appropriate information is relayed. However, the European heart rhythm association (EHRA) highlight that driving advice can be conflicting and inaccurate, and gaps are evident between recommendations and patient compliance post-

implant (Vijgen et al., 2009). Moreover, restrictions on driving mean relying on a taxi to get to work or appointments leading to an additional financial burden on the already existing burden. Younger ICD recipients and male ICD recipients have revealed their experiences of being unable to work for some time, with some having to change employment or retrain for new roles and worried about finances (Jakub, 2018; McDonough, 2009).

As discussed earlier, the support from cardiac rehabilitation programmes was important to some participants, however, many were not referred to a programme. Cardiac rehabilitation programmes aim to reduce mortality and morbidity and improve patients' quality of life and involve exercise components (Berg et al., 2015; Frizelle and Lewin, 2004). However, a Cochrane review identifies those patients with ICDs are often excluded from cardiac rehabilitation programmes (Nielsen et al., 2019). This may be due to fear of inducing arrhythmias during exercise. A pilot rehabilitation programme has highlighted a common belief that too much exercise and excitement can cause the ICD to activate (Frizelle et al., 2004). However, some studies have reported that exercise was not associated with increased shocks, adverse events or complications, particularly in heart failure patients with reduced left ventricular function and ICDs (Lampert et al., 2017; Piccini et al., 2013). It has also been found that people living with an ICD who attended a cardiac rehabilitation class felt safe and secure because of the safe exercise regime and their heart was monitored closely which led to an improvement in confidence (Berg et al, 2015; Fitchet et al., 2003). Participants in this current study placed importance on redefining their life in order to manage their fears; a finding also reported in Dickerson's (2002) secondary analysis of three earlier phenomenological studies. In addition, many participants employed numerous strategies to overcome their fears anxieties and uncertainties of everyday life. Living with uncertainty is an ongoing process with an ICD, whilst learning to accept the reality of their life, as revealed in a longitudinal study over one year with ICD recipients (n=56) (Flemme et al., 2011).

7.5 Lived Time

Time was recognised as invaluable; all aspects of participants' experience was influenced by time. In keeping with Heidegger's tenet 'temporal', the particular meaning placed on time emerged as a significant contributory factor in gaining acceptance. Acceptance of living with an ICD was a gradual process over time. Acceptance of the ICD involved adapting to 'the alien within' and reaching an understanding that this 'alien' determined the person's ability to undertake daily activities. Each participant responded in their own unique way. Some participants were thrust swiftly towards acceptance. Others struggled through phases before reaching acceptance. This was more evident in participants who had experienced a cardiac arrest. Using Kubler-Ross's theory of grief, Asghari and Arabi (2019) compare the process of illness acceptance and reveal the stages of shock and denial, anger, bargaining, depression and acceptance among 15 people living with an incurable illness. The first stage of grief is denial which is often a defence mechanism allowing the individual to come to terms with the shock of the diagnosis.

Several participants referred to being shocked by their initial diagnosis and the need for a defibrillator, others were overwhelmed by having had a cardiac arrest as they had no previous cardiac history, this was the first encounter with 'Being towards Death' which resulted in their need for an ICD. As a result, a number of emotions emerged including anger. The second stage of denial of anger was also an aspect of some participants' experience. Anger, as a consequence of needing an ICD implanted in the first instance and how it may impact on their future. The third stage of bargaining was evident in participants' attempts to make lifestyle changes to avoid increasing their heart rate or becoming dizzy preventing the onset of a shock from the defibrillator. This approach is viewed as ICD recipients' attempt to bring some control to their lives (Mc Donough, 2009). The fourth stage, depression, was evident in participants' expressions of feeling overwhelmed and out of control, questioning their purpose in life. The fifth stage of acceptance was the turning point for many. Lim (2013), in an examination of Kubler-Ross's theory, equates this acceptance to the stage of

realisation (Lim, 2013). However, for some, this took considerable time. Individuals do not necessarily go through each stage of this process when grieving or go through the process in any particular order (Lim, 2013). No perspective is the correct one; and a literature review of acceptance and denial depicts the individuality of responses to illness (Telford, Kralik and Koch, 2006).

Qualitative research with younger ICD recipients reveals that life does become easier with time (Mc Donough, 2009), and reference to time was noted as a key factor for many study participants in this current study. With time, their pain subsided, life improved and activities were resumed. With acceptance over time, there was a healing of the body and mind. A relationship between a patient's well-being and acceptance of illness is also revealed in a number of studies (Evers et al., 2001; Karademas, Tsagaraki and Lambrouk, 2009; Karinar, 2007).

However, *being accepting* for study participants who never experienced a cardiac arrest and or a shock from the device and whose ICD was implanted as precautionary, was challenging. Nevertheless, Pedersen et al. (2009) argue that there is no evidence to support the view that those with ICD's implanted for primary prophylaxes have more distress or poor quality of life than those implanted for secondary prevention. However, in this current study, *being accepting* came earlier for the participants who thrust themselves into caring for others, joined community groups for support, resumed exercising or returned to work. Those who accepted the device as lifesaving rather than a threat to their mortality expressed fewer concerns.

Resilience may also have contributed to participants' acceptance. This assertion is based on the study's findings that older participants appeared to accept their ICD more readily than younger participants and the influence of previous experience such as prior trauma can contribute to older people's resilience (Brockie and Miller, 2017; Hoelterhoff and Chung, 2017).

A positive meaning can be associated with a disease, by recognising a positive outcome arising from a stressful situation (Evers et al., 2001). Moreover, acceptance of an ICD has been attributed to feelings of safety and security (Mc Donough, 2009) and involves recognising the need to adjust as well as deal with uncertainty and adverse consequences of chronic disease (Evers et al., 2001). However, younger participants with young children voiced fears and concerns about their children receiving a similar diagnosis and requiring an ICD. Similar findings concerning passing on the disease have been highlighted among younger ICD recipients (McDonough, 2009). A few of the younger participants had their ICD implanted for Channelopathies. As discussed in Chapter one, p 29, Channelopathies is a disturbance of the electrical activity of the heart causing ventricular tachyarrhythmias which could potentially lead to sudden cardiac death. These abnormalities can be inherited affecting first degree relatives placing them at considerable risk (Linder et al., 2013). In addition to coming to terms with their diagnosis, participants were concerned that their children may also have inherited the gene. Concerns, anxieties and fears for their children's futures took precedence.

Individuals are also shaped and changed by their social environment (Greve and Staudinger, 2006). As time fades the construction of meaning relating to personal concerns change and questions relating to the future arise (Brandtstädter and Rothermund, 2003). It is acknowledged that people's perspectives change over time whilst attempting to make sense of their experience with chronic illness (Paterson, 2001). However, the findings also suggest that participants' acceptance was influenced by their personal choice to do so. The realisation that they could not change their situation forced a change, demonstrating what Heidegger (1926) refers to as finding their authentic self, and captured by Victor Frankl's view that:

"When we are no longer able to change a situation, just think of an incurable disease, an inoperable cancer – we are challenged to change ourselves"

(Frankl, 2004. p.116).

7.6 Conclusion

This chapter has discussed the experience of participants living with an ICD and revealed that participants were living with ‘an alien’, one that threatened their mortality but also one they relied on for survival.

From a Heideggerian stance, ‘Being with Others’ enabled participants to demonstrate their ‘Authentic self’, choosing to live with and accept the ‘Present to Hand’ alien that resided within their body that prevented them ‘Being towards Death’. To gain authenticity individuals must learn to fully accept themselves (Carson and Langer, 2006). Only they could attach meaning to the event, although supported, were forced to design their own plan to adapt to this lifestyle change. As with other life-threatening illnesses, acceptance was key. Their ability to accept was aided by the passage of time. Acceptance shaped their attitude towards death and the vision of the future.

From an existential stance, the ICD forced participants to adapt, accept and embrace the new body where an alien resides in order to achieve any fulfilment of life. Awareness and understanding of participants’ experience of this specific phenomenon contribute to the body of existing knowledge and will inform healthcare professionals. The following chapter will address recommendations for policymakers, practice, and future research.

Chapter Eight: Conclusion

8.1 Introduction

This concluding chapter addresses the significance of the findings, focuses on the contribution to knowledge, recommendations for practice and policymakers and finally the study's strengths and limitations.

This study contributes to knowledge through (a) its topic (b) its methodological approach and (c) its findings.

8.2 The Topic

The topic contributes to the field through its focus on understanding the experiences of individuals living with an ICD in Ireland. It offers an understanding of the challenges that living with an ICD presents. It reveals the role of support from cardiologists, cardiac investigation teams, and specialist nurses. However, it highlights the lack of specialist support, particularly available in rural areas. It provides an understanding of the inequalities in services between rural and urban locations. It draws attention to the lack of specialised support for ICD recipients who are not managed at the country's specialised centre. Moreover, it highlights individuals' lack of understanding and the need for information following discharge from hospital. It also highlights the need for local policies and protocols and adherence to the recommended ESC/ACC guidelines. Finally, the topic uncovers implications for services and policymakers to address in supporting all individuals living with their ICD.

8.3 Methodological Approach

This is the first known study exploring the experiences of individuals living with an ICD using a methodological approach underpinned by Heidegger and Ricoeur.

The methodology was used creatively by drawing on Heidegger, Ricoeur and van Manen in order to remain true to their philosophical underpinnings. As the researcher's interest was to reveal the lived experience, Heidegger's

philosophy was the most appropriate methodology to explore this phenomenon, with its focus on ontology, centring on experience and how the world influences the individual and their experience (Marable, 2011).

8.4 Significance of the Findings and Contribution to Knowledge

This is the first known study exploring the experiences of ICD recipients in Ireland. Participants' experience of living with an ICD revealed social structures that impacted negatively on their individual social capital. These negative social structures served as a barrier to participants in accessing services and supports, thus their opportunity to exercise their individual agency to accept and live with an ICD.

For participants living remotely poor infrastructure was a particular social structure negating their agency to access services. Participants were restricted from driving, resulting in their exclusion from the support offered by centres of excellence. Ireland's poor infrastructure, and its inadequate public and private transport service further diminished many participants' social capital limiting their access to these centres and support networks necessary to facilitate participants' individual agency in accepting and adapting to living with an ICD. Thus, inability to adequately access the valuable resource of centres of excellence and the experts within these centres resulted in participants being denied the opportunity to appropriately avail of an expert supportive network and benefit from this network. This lack of adequate opportunity to avail of services shaped by the social structure of poor infrastructure arguably resulted in the delivery of an inadequate service to participants who lived remotely negating their individual agency and self-efficacy to accept, adapt and transition to living with an ICD.

From this perspective, this study has contributed to knowledge revealing the negative impact poor infrastructure has had on participants' individual agency. Their capacity to avail of social relations in the valuable resource of expert knowledge and skill in centres of excellence has negatively impacted on their individual personal goals to accept and adapt to living with an ICD.



Figure 8.1 Contribution to Knowledge and Recommendations.

8.5 Implications and Recommendations for Practice

8.5.1 Information and Support

The recommendations for practice as outlined in the European Society of Cardiology (2015) guidelines recommend that information should be provided pre-implantation (Piori et al., 2015). This includes information concerning deactivation and should be discussed during consent.

Inadequate social structures reported in the findings has implications for each implantation site. Government policy needs to consider adequate provision of services to populations who are living remotely ensuring that health care provision is equitable for all. It exposes the imperative to consider virtual mediums such as telehealth to support the opportunity for individuals to access expert support and advice both pre and post-operatively increasing their agency toward self-efficacy and self-determination in adapting to living with an ICD.

The coronavirus pandemic has led to many changes in the delivery of healthcare locally and globally and highlighted that both patients and healthcare staff are familiar and comfortable with the delivery of virtual clinics through telemedicine. This has resulted in an accelerated move towards telehealth with the launch of the HSE's pilot 'Attend Anywhere' initiative in late 2020 where patients have access to virtual clinics with a range of health care professionals. Such initiatives will diminish the barriers to information and support due to inadequate infrastructure illuminated in this study.

8.5.2 Social Support

Public awareness campaigns are needed to improve the public's perception of ICDs. Social capital and social support could be increased by public awareness of the impact of an ICD on people's lives through media campaigns. Family and friends are cautious of adverse events occurring when socialising with this particular group. This approach should limit their fears.

The development of regional support groups is needed for ICD recipients. Local support groups could initially meet the needs of individual linking with regional groups as a support to lobby for improved services.

8.5.3 Healthcare Support

The guidelines recommended by the European Society of Cardiology should be implemented into current practice (Priori et al., 2015). Additionally, local evidence-based protocols and policies in keeping with the ACC/ESC guidelines are needed in each implantation site.

Internationally the role of Advanced Nurse Practitioner (ANP) has been in existence for fifty years and was first established in the Republic of Ireland in 2001 and noted as having a beneficial impact on patient care generally (Kerr and Macaskill, 2020). A Cardiac Rehabilitation (ANP) or Cardiology ANP post with both a community and hospital remit to include patients with ICD patients should be available regionally. This ANP should liaise with all implantation centres, evidence-based policies, accept referrals, assess patients and refer appropriately to cardiac rehabilitation classes specifically designed for their needs.

A key specialist contact number should be available as a link by email, Zoom or telephone contact on discharge. All follow up checks should involve an appointment with a key specialist to provide time to address any queries or problems.

Clinicians should explore the possibility of alternate implantation sites with patients before implant as younger female participants voiced concerns relating to the visible bump and scar.

8.5.4 Education

ICD users in Ireland need structured support systems. This entails the provision of prompt appropriate information before discharge and follow-up after discharge. Standardised information should be available for inpatients on all units that admit ICD patients with visual representation explaining pre, peri and post-implantation of an ICD. In non-emergency situations, all

patients needing an ICD should be shown the model of ICD before the implant.

Easy to read relevant booklets with appropriate illustrations suitable for all age groups with ICD related conditions should be available in all cardiac units. Consideration should be given to the development of Infographics, and appropriate pictures should be included that are representational of all of the ICD population. Many individuals felt that this was not the case.

8.5.5 Psychological Support

The European Society of Cardiology guidelines highlight that a suitable assessment and treatment of psychological distress is vital to clinical management as well as support on how to live with the device (Priori et al; 2015). A simple measure to evaluate patients' level of distress before discharge should be introduced. The Distress Thermometer (DT) and its standardised 32-item problem list could be used. All ICD recipients should be referred to a psychologist prior to the procedure in non-emergency situations. All ICD recipients should be reviewed by a clinical psychologist following discharge home.

Remote monitoring should be available to all ICD recipients offering additional security to those residing remotely. This is now a service offered by many device manufacturers.

8.6 Recommendations for Policymaker

Integrated care has become central to health policy reform across Europe over the last decade improving both patient satisfaction and outcomes (Doocey and Reddy, 2010). Ireland appears to be lagging behind their European counterparts in this field. Sláintecare (2020) recommends a model of care that shifts from acute hospital to the community. Currently, the focus is on older people, scheduled and unscheduled care, critical care and chronic diseases (Kerr and Macaskill, 2020). This model of care should be considered for ICD patients particularly those living in rural locations in Ireland.

The Irish healthcare the HSE People Strategy (2015-2018) and Sláintecare (2020) are implementing policies and procedures to target, support and develop roles of key health care workers such as ANPs to tackle deficits in care to ensure the best care is delivered to those in need. Based on these recommendations for care groups a similar Cardiology/Cardiac rehabilitation ANP post should be available to support this particular care group post-discharge and address their many concerns. Implementing the ANP post would ensure ICD patients would receive the service they are entitled to.

Discharge information is inadequate and mainly provided by literature, the HSE should devise a national strategy outlining specific guidelines for healthcare professionals. This should be based on clinical guidelines from scientific societies such as the European Cardiac Society and American Heart Association addressing best practices.

The benefits of exercise are widely acknowledged. Supervised exercise such as Cardiac rehabilitation should be available for all ICD recipients. MedexUL established a successful chronic disease rehabilitation programme that included supervised exercise and educational classes in a community setting in 2017 (O'Connor et al., 2020). A similar model should be made available for ICD recipients in various locations within each county.

8.7 Recommendations for Future Research

The European Society of Cardiology recommends that more research is necessary to create evidence-based interventions to enhance care and ease the psychological effects for patients and families at risk of sudden care disease (Piori et al., 2015).

As discussed in chapter six, participants' acceptance emerged as an overarching finding. Further exploration should focus on what factors influence early acceptance. Moreover, further research could explore what factors contribute to resilience among ICD recipients. Finally, the study

revealed the differences in the information provided to those that had a previous cardiac arrest or had a definitive cause for their cardiac arrest and further research in this area is needed to compare information and support provided in primary and secondary implantation.

8.8 Strengths and Limitations

A strength of this study was the researcher's extensive clinical experience and knowledge of cardiology. This possibly contributed to participants' willingness to share their experiences. This also resulted in gatekeepers' support at the three sites where participant recruitment was undertaken and subsequent access to a large number of people with ICDs nationally from both urban and rural settings. The inclusion of ICD recipients from a range of different geographic locations has explicated a deep understanding of their lived experience. Employing Heidegger's hermeneutic phenomenology and Ricoeur's theory of analysis contributed to the richness and uniqueness of the study findings. Moreover, by framing the discussion in van Manen's (1990) lifeworlds a holistic appreciation of participants' lived experience was explicated. A good gender and age balance was also achieved adding to the study's potential for a wide relevance. Finally, using NVivo 11 to assist in managing the analysis has resulted in ensuring transparency in the process.

However, because participants were recruited from cardiac clinics only, it is unknown how many potential participants were excluded. In keeping with hermeneutics, I chose to conduct unstructured interviews allowing the participant's story to flow naturally, probing only for clarification. Undertaking unstructured interviews may have resulted in relevant information not being asked about as would happen when using a semi-structured interview guide. In addition, the findings are based solely on the researcher's understanding and interpretations, and a team-based analysis may have revealed a different interpretation. While researcher reflexivity was viewed as paramount throughout all stages of the study, it is possible that overemphasis was placed on particular aspects concerning participants' journey due to the researcher's knowledge and background. In keeping with

phenomenology, this study was never intended to be generalisable, and the findings pertain only to the cohort of individuals from whom the information was obtained. However, evidence of transferability was demonstrated by means of an audit trail as discussed in Chapter four (p125) providing rich descriptions of the research process and clearly outlining the steps taken whilst conducting this study.

This study brings a unique contribution to the current knowledge of living with an ICD. Living with an ICD requires acceptance of the 'alien' within and those who have an ICD following a cardiac arrest experience a somewhat different journey of acceptance compared to those with an ICD inserted for preventive reasons. Having this understanding can guide healthcare professionals to deliver more person-centred care to those living with an ICD.

8.9 Conclusion

This study explored the experience of individuals living with an ICD and revealed their experience of living with an 'alien' whom they relied on for their survival and this knowing impacted significantly on their lives. If the body is to heal and function effectively the mind must also heal. Although it is evident from the literature that many advances in ICD technology have occurred over the years, considerable gaps remain pertaining to care, particularly concerning the psychological care for ICD recipients. The individuals that attend specialist services in Dublin have a direct link to their named clinical nurse specialist who in turn has direct access to a cardiologist. These individuals are assured that their concerns are addressed promptly either by email or telephone. However, those individuals living remotely do not have this experience and would benefit most from this type of service.

Addressing psychological issues may positively influence physical issues. Access to a support group located locally was voiced by a number of participants, and the only known support group is located in Dublin and travel to attend this support is not an option for many. Moreover, health

service providers enacting policy need to be aware of the impact of the ICD on an individual's mental health and reallocate funding to include psychological support to all those receiving ICD implants. Psychological support is necessary for recovery and acceptance, therefore allocation of funding to create a psychological service is necessary.

This study contributes to the existing literature on ICDs, which is mostly quantitative in approach. This study's contribution is significant as participants were recruited from three sites in the Republic of Ireland, resulting in a balance of urban and rural participants' experiences. The study has revealed the unique challenges experienced by those living in rural areas where social structures impacted negatively on individual social capital. These negative social structures served as a barrier in accessing services and supports and participants' opportunity to exercise their individual agency to accept and live with an ICD.

The study also highlights that living with an 'alien' is an embodied experience that affects all lifeworlds in a 'living towards death' experience. Furthermore, acceptance of this 'alien' is important to restore normality and achieve a reasonable quality of life. Choosing to accept is a choice but requires considerable support and time. Participants' perception of the 'alien' was important and rather than viewing the device as restricting and hindering, they needed to adopt a perspective of it being enabling and purposeful.

This study has provided an understanding of the experience of living with an ICD. Although other studies have revealed similar findings, the uniqueness of this study is that it draws on a number of philosophical worldviews which guided the researcher's interpretations and understanding of each participant's unique experience. Some of the findings in this study add further to existing knowledge but specific new knowledge has also been revealed. It is hoped that the rich findings revealed can present a vivid account of the overall experience of individuals living with an ICD, which will guide practice, policy and future research.

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Appendices

Appendix 1: CASP Table (Y=YES, C=CAN'T, TELL N=NO)

s		1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between the researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
1	Abassi et al 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2	Bolse et al 2007	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
3	Coneliius 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4	Flanagan et al 2010	C	Y	Y	Y	Y	Y	Y	Y	Y	Y
5	Garrino 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6	Humphreys et al 2016,	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
7	Kamphusis 2004	Y	Y	Y	Y	Y	C	Y	Y	Y	Y

8	McDonough 2009	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
9	Mert et al 2012	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
10	Morkin et al 2010	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
11	Ooi et al 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
12	Palacios- Ceña et al 2011	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
13	Palacios- Ceña et al 2011	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
14	Pasyar et al 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
15	Pederson Et al 2016	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
16	Saito 2012	Y	C	C	Y	Y	C	Y	Y	Y	Y
17	Zayac and Finch 2009.	C	Y	Y	Y	Y	Y	Y	Y	Y	Y

Appendix 2: Data Extraction Table

#	Author	Year	Country	Design/Method	Sample	Analysis	Study Focus	Themes Generated
1	Abbasi,	2014	Iran	Interpretative phenomenological approach.	Thirteen participants (seven men and six women) between the ages of 21 and 70 years old (mean = 58.15, SD = 14.4). The duration of having an implantable cardioverter defibrillator was 1 - 120 months. Maximum variation sampling Semi-structured interviews.	van Manen's six steps	To understand the challenges of patients with Implantable Cardioverter Defibrillator.	Fear Concerns re the future Concerns re device malfunction.
2	Bolse et al	2007	United States	Phenomenographic approach. Semi-structured telephone interviews.	Fourteen participants (eight men and six women), aged 21–84, strategically	Dahlgren and Fallsberg's seven steps	To describe how a selected group of patients with an implantable cardioverter-	Trust (Trust related to organisations). Adaptability (How patients adapt)

					selected		defibrillator perceived their life situation.	Empowerment (Support from family and Friends)
3	Conelius	2015	United States	Descriptive phenomenology	Three participants. (All Caucasian women). age range: 34–50 years average 1 year with ICD	Colaizzi's approach.	To describe the experiences of women with ICD implantation	Security blanket Piece of cake A constant reminder Living on the edge Catch 22 I'd rather not have it
4	Flanagan et al.	2010	United States	Descriptive phenomenology	Purposive sampling. (Fourteen participants eight males, six females median age: 55.7 years (range: 21–48 years) Ten for secondary prevention- average 1–2 years with ICD. Six experienced shocks in 1st post-op year	Van Manen's hermeneutic phenomenology approach.	To explore lived experiences of patients with 1–2 years post-ICD implantation	Appreciation versus apprehension. Maintaining structure and routine as a way of maintaining a sense of self. Isolation and vulnerability. Being abandoned and Still grieving. Seeking advice, Making decisions.
5	Garrino	2018	Italy	Descriptive	Interview data from	Giorgi approach	To explore ICD	Living in fear.

				phenomenological method	a purposive sample of twenty ICD recipients. Of the 20 participants (5 women and 15 men. Eight patients were between 40 and 50 years old, two were younger, and all others were over 50 years of age, including two individuals over 70.	analyses were done using a descriptive phenomenological method, based on qualitative	recipients' experiences in order to foster improvements in the quality of care.	relying on technology. knowing about the ICD how to live with it. coping with the effects of the ICD in daily life. Anger amongst younger participants.
6	Humphreys et al	2016	England	A descriptive study using a semi-structured interview.	A purposive sample of eighteen recipients (11 males and 7 females) aged 28 – 66 years old who had either received or not received an ICD shock was conducted.	Analysed using the thematic approach using Braun and Clarke guidelines.	To explore the lived experience of implantable cardioverter-defibrillator (ICD) recipients.	physical consequences. emotional consequences (Feeling vulnerable and uncertain; anxiety and depression). (Coping with the ICD (avoidance/restrictive behaviours. acceptance; concealment)

7	Kamphuis et al	2004	The Netherlands	Descriptive design. The semi-structured interviews were based on insights gained from a literature review.	Purposive sample. A sample of twenty-one patients (12 males and nine females) Average age 58.3 years (47.2–69.4) who received an implantable cardioverter-defibrillator was interviewed during three consecutive periods: one, six and twelve months post-discharge from the hospital.	The transcripts were subjected to content analysis	To explore how implantable cardioverter-defibrillator recipients perceive their lives during the first year after implantation of the device.	Physical deterioration Cognitive changes Perceived social support, Dependency, contact with the doctor, Confrontation with mortality uncertainty surrounding having a shock. Anxiety, anger, uncertainty, disappointment, frustration, Unexpected barriers, Acceptance and dependency
8	McDonough	2009	United States	Descriptive qualitative Telephone interviews. Internet interviews and recruited through Zaplife.org Fieldnotes.	Purposive sampling with maximum variation sampling (Twenty participants) Young adults aged 18–40 years Fourteen Internet group	Thematic analysis using a framework approach. Nvivo 7 for data management.	To describe the everyday experiences of younger adults (18–40 years) with ICD. To describe the physiological and psychosocial issues of younger adults. To identify the coping	Four descriptive categories: Psychosocial, developmental Physical, and economical. Themes psychosocial category returning to normal,

					six males, eight females mean age: 32.9 years average of 4.1 years with ICD		strategies	mood disturbances, anger body image concerns. Themes developmental category unique to young adults: childbearing and childrearing, Themes physical category expectation regarding physical activity, economical category, the issue of financial security.
9	Mert, et al,	2012	Turkey	Descriptive approach. Focus group interviews were used to obtain data	Purposive sampling. Nineteen patients, four were females and 15 were males with a mean age of 53.57±13.44 years who have implanted cardioverter defibrillator at two centres in Izmir,	Analysed using qualitative content analysis	To describe the experiences of patients with implantable cardioverter-defibrillator (ICD).	Activities of daily living, social life, familial relationships, emotional changes, anger implantable cardioverter-defibrillator shocks experiences with receiving information

					the patients were assigned into four groups.			counselling from health care providers
10	Morken et al,	2010	Norway	Grounded theory	Purposive sampling. Semi-structured interviews were performed with sixteen persons (11 males and 5 females) aged 25-80 years old living with an implantable cardioverter-defibrillator.	Strauss and Corbin's 1998 Grounded theory.	To explore implantable cardioverter-defibrillator recipients' experience Of living with an implantable cardioverter-defibrillator over time.	Core category 'Reconstructing four categories: 'Losing control'; 'regaining control'. 'Lacking support'; and 'seeking support'
11	Ooi et al,	2018	Singapore.	Descriptive Qualitative design	Sixteen participants were recruited. Thirteen were male and three were female. (Age ranges 52 to 84 years old) were purposively recruited and interviewed individually for this	Data collected were analysed using thematic analysis.	To explore perceptions towards the quality of life, coping strategies, and learning needs of patients living with ICDs in Singapore.	Seven themes emerged (1) experiencing ICD shocks, (2) ambivalent love-hate relationship with the ICD, (3) receiving support from Healthcare professionals

					exploratory qualitative study.			and social networks, (4) attaining acceptance and returning to normalcy, (5) physical coping, (6) emotional coping, and (7) readiness and the need for enhanced patient education
12	Palacios-Ceña et al. (A)	2011	Spain	Descriptive phenomenology First phase unstructured interviews. Second phase semi-structured interviews.	A purposeful sampling of twenty-two male participants with a mean age of 66 attended at the defibrillator consultancy at the Hospital. A secondary, theoretical sampling was also carried out to gain a more in-depth understanding of	Giorgi approach	To determine the experience of Spanish male ICD recipients	Accepting the change. Developing strategies. Rethinking your relationship with your partner and becoming more emotionally distant. Giving up some of your independence. Transformed. Continual uncertainty and waiting. Living with an insurance policy.

					<p>certain aspects identified in the first sampling, such as living with the discharges and difficulties during sexual activity.</p> <p>Phase 1: Purposive sampling</p> <p>Phase 2: Theoretical sampling</p> <p>(Twenty-two participants, men above age 18 years average 44 months with ICD. seventeen for secondary prevention ten experienced shocks</p>			
13	Palacios-Ceña et al. (B)	2011	Spain	Phenomenological study guided by Husserl's.	Data were collected from twenty elderly Spanish men aged 72 -82 years. Sampling was purposeful and used the snowball	Giorgi method.	To determine the experience of elderly Spanish men	<p>Accepting change</p> <p>Developing strategies.</p> <p>Living with someone</p> <p>Feeling transformed</p> <p>Live feeling safe.</p>

					technique.			
14	Pasyar	2017	Iran	Phenomenology interpretative	Ten patients (six men and four women) ranging from 24 to 74 years. purposive sampling. Semi-structured interviews.	Van Manan method	To identify and describe the patients' experiences of living with ICD	4 themes and 11 subthemes Themes "Compromised self-identity" "Crossing the border of the unknown", "Fluctuation in the adjustment path", "Surrounded by changes". Sub-themes Loss of prestige Changes in body image Being hurt by the battery label Unpredictable situation Rise and fall Internal turmoil Wandering to cope with ICD The institutionalization of ICD in life Family changes Social role changes

								Change in the manifestation of routines
15	Pedersen et al,	2016	Denmark	Mixed methods	Total of 389, 317 males and 72 females, average age 65. Three semi-structured open-ended focus group interviews with (six-eight) ICD.	Descriptive qualitative	To examined patients' needs and preferences for information provision and care options and overall satisfaction with treatment.	The level of satisfaction with information provision was high. Psychological support for patients (39.9%), their relatives (43.1%), and deactivation of the ICD towards the end of life (47.8%) were among the top five topics that patients reported to have received no information about. The top five care options that patients had missed were talking to the same healthcare professional (75.2%), receiving on-going

								<p>feedback via remote monitoring (61.1%), having a personal conversation a staff member 2–3 weeks post-implant (59.6%), having an exercise tolerance test (52.5%), and staff asking how patients felt while hospitalized (50.4% Patients with a secondary prevention indication and cardiac arrest survivors had specific needs, including a wish for a psychological consult post-discharge.</p>
16	Saito et al,	2012	Japan	Descriptive. Semi-structured interviews	Twenty-two outpatients' participants. Twenty male and two females aged 35-79		To describe the illness experience.	<p>Theme. Bewilderment Sub-theme (Uncertainty, fear) Theme. Facing reality</p>

								Sub-theme Able to continue life managing activities. Theme: Giving meaning. Sub-theme Recognising their disease.
17	Zayac, S., Finch,	2009	USA	Systematic qualitative review	A systematic search of the scientific literature uncovered 153 studies of which 12 met the following inclusion criteria: qualitative English research of psychological adaption to the implantable defibrillator or qualitative literature reviews.		To investigate recipient adaptation issues to the ICD.	Perception of fear, Perception of anxiety, Perception of device and device dependence. Perception of support Perception of information.

Appendix 3: Ethical Approval



Research Ethics Committee
Sligo University Hospital
Chairperson: Dr. Miriam O'Sullivan
Admin: Aileen Concannon

Orla Noonan Sweeney
Avaltygort
Killygordon
Co. Donegal

23rd January 2018

Re. Research Ethics Application/Amendment

Dear Ms Noonan Sweeney

The Research Ethics Committee (REC) at Sligo University Hospital has received your amendment for ethical review of the study "*Exploring the experience of living with an implantable cardiac defibrillator (ICD). A Heideggerian phenomenological study.*"

The amendment underwent expedited review and the REC Chairman has given a favourable ethical opinion for the study for Sligo University Hospital.

Documents reviewed:

- Amendment notification Form
- Appendix 19 amended
- Appendix amended Introductory Letter
- Protocol Amended

The REC requires that approved studies submit an annual report to the REC as per your original approval.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Miriam O'Sullivan", is written over a light blue horizontal line.

Dr. Miriam O'Sullivan
REC Chairperson



Leas-Uachtarán
um Thaighde

Vice President
for Research

13 September 2017

Ref: 17-Sep-20

Orla Noonan Sweeney
Avaltygort
Killygordon
Co Donegal

Dear Orla,

Re: 'Exploring the experience of living with an implantable cardiac defibrillator (ICD). A Heideggerian phenomenological study'

I write to you regarding the above proposal which was submitted for ethical review. I am pleased to inform you that your proposal has been granted **APPROVAL**.

It was noted that the study is clearly outlined and extensive and satisfactory information is provided on precautions to be taken around risks to participants and the researcher, as well as information on data storage etc.

All NUI Galway Research Ethic Committee approval is given subject to the Principal Investigator submitting annual and final statements of compliance. The first statement is due on or before 13 September 2018.

When the decision was taken I was chairing the meeting and the following members were also present:

Dr Kevin Davison

Dr Cormac Forkan

Dr Brian Hallahan

Dr Martina Kelly

Dr Kiran Sarma

Mr Patrick Towers

See annual and final statement of compliance forms below. Section 7 of the REC's Standard Operating Procedures gives further details, and also outlines other instances where you are required to report to the REC.

Yours sincerely

Jane Walsh

Acting Chair, Research Ethics Committee

THIS NOTEPAPER MUST NOT BE USED FOR
PRESCRIPTIONS OR INVOICING PURPOSES

HOSPITAL, DUBLIN
INCORPORATING
THE NATIONAL CHILDREN'S HOSPITAL

Ms Orla Noonan Sweeney
ADON/NSM
Nursing office
Letterkenny University Hospital
Letterkenny
Co Donegal.

30th August 2017

Re: Exploring the experience of living with an implantable cardiac defibrillator (ICD)

REC Reference: 2017-08 Chairman's Action (8)
(Please quote reference on all correspondence)

Dear Ms. Noonan Sweeney,

The REC is in receipt of your recent application to _____ I Research Ethics Committee
in which you enquired about ethical approval for the above titled research.

The Chairman, _____, on behalf of the Research Ethics Committee, has reviewed
your application and granted ethical approval for this study.

Yours sincerely,

Secretary

Ethics Committee operates in compliance with and is constituted in accordance with the European
Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.



*General Manager's Office,
Letterkenny University Hospital, Letterkenny Co. Donegal
F92 AE81*

Telephone: (074) 9123501

Fax: (074) 9104651

17th October 2017

Ms. Orla Noonan
ADoN/Night Service Manager
LUH

Re: Ethics Application
Exploring the experience of living with an implantable cardiac defibrillator (ICD). A Heideggerian
phenomenological study

Dear Ms. Noonan,

I am writing further to your recent attendance at the Ethics Committee meeting held on Thursday 12th October 2017.

The Research Proposal referred to above has been approved by the Committee.

On behalf of the Committee can I wish you well with your proposed study.

Yours sincerely

Mr. Seán Murphy
General Manager

Appendix 4: Patient Information Pack

Appendix 4(A): Researchers Introductory Letter

Title of study: Exploring the experience of living with an implantable cardiac defibrillator. A Heideggerian phenomenological study.

My name is Orla Noonan Sweeney, and I am working as an Assistant Director of Nursing/Night service manager in Letterkenny University Hospital, Co Donegal. Prior to this appointment I was working for 15 years in the Cardiac rehabilitation department as Clinical Nurse Specialist. I am currently a student in the National University Hospital in Galway undertaking a PhD in Nursing Studies. As part of the PhD, I am conducting a research study to understand what it is like to live with an implantable cardiac defibrillator (ICD). I am interested in speaking to individuals aged 18yrs or over who have an implantable defibrillator.

Appendix 4(B): Participants' Information Sheet

Title of study:

Exploring the experience of living with an implantable cardiac defibrillator. A Heideggerian phenomenological study.

Aims and purpose of this research

The purpose of this research is to understand your views of what it is like to live with an implantable defibrillator. This study will contribute towards a greater understanding of the perspective of an individual experiences living with an implantable cardiac defibrillator (ICD).

Why is this research important?

There have been several studies done which focus on implantable cardiac defibrillators (Sears, 2008; Strachan et al., 2012; Groarke et al., 2012; Joyce et al., 2013; Rahman et al., 2012). However, there is little information available on the experiences of people living with the ICD. Therefore, your experiences, thoughts, and views are of utmost importance as they will give greater insight on what it is like to live with the device. This information may support others adjusting to their device. It can also be used to inform service provision as it will furnish healthcare providers with a greater awareness of your needs.

What will I have to do if I decide to participate?

If you decide to participate, you will need to sign the consent form, a copy of which is included herewith. As you are older than 18 years of age you can consent to participate yourself. Once you have consented, you can return it to me in the stamped addressed envelope provided. Becoming a participant means that I will interview you using a tape-recorder for about 45-60 minutes. However, this may be for a shorter or longer period depending on what you want to say. In reality I will be asking you to tell me your story of what being a patient with an implantable cardiac means from your view and your experience. The interview will be held at a mutually agreeable location such as in a meeting room in a hotel, your GP surgery or a meeting room in your local hospital

Possible benefits from this research

By participating in this research study, you will have the opportunity to reflect upon as-well as share your experience. The information that you can provide is important to our understanding of what it is like to experience living with an ICD. The findings of this study will have the potential to inform and assist policy makers in making informed decisions around future resource and allocation planning for patients who have an implantable device.

Foreseeable risks and consequences of participation in this study

There are no physical risks associated with participating in this study. There is always a chance that discussing some issues may upset you. Should you become upset during the interview, you will be invited to take a break if you wish, and the audio-recording will be turned off or the interview stopped totally which ever you request. I will respect the decision to stop the interview at any time and there will be no negative consequences. After the interview, if you feel you require further support the name and contact details of the Cardiology Nurse specialist, support groups and psychology department will be provided.

Your rights within this study

You have the right to completely voluntary participation. You have the right to decide not to participate at any time, even in the middle of an interview, with no negative consequences. There will be a green disk on the table in front of you, if you need to stop the interview, you simply turn it over so that the red side is facing upwards, and the interview will end. You have the right to be listened to attentively and given respect for your opinions and experiences to add value to the research. You have the right not to answer any question should you decide, without necessity to disclose the reason to anyone. You are entitled to withdraw from this study at any time should you wish, without any penalty. If you decide not to participate in the study at any time, I would ask that you send an email or phone declaring withdrawal to details enclosed.

Confidentiality

Confidentiality is extremely important when undertaking research and a number of measures will be engaged to ensure your confidentiality is

completely protected within this study. The interview will be private; no one will hear the audio tape except for me and a professional transcriptionist. The transcriptionist is the person who writes down everything you have said and will have signed a form promising to keep everything confidential. When I write the final report, if there are any details that could identify you in the data, I will change them so that no one could possibly figure out who the participants were. The transcript and audio-tape of your interview will not use your real name. Instead, it will use a false name known as a (a pseudonym).

Who will know about what I said:

When I write up your interview transcript, I will put a code on it and remove any material that could possibly identify you. I will be discussing my findings with my research supervisor, but during these discussions I will ensure that the data material has been coded and that all potential identifiers have been removed. I will be writing the findings in my research study and in time, my intention is to present these findings at conferences and as publications. However, for all of these processes, codes will be used to present data with no personal identifiers. All data linked with this study will be securely stored and destroyed within five years of completion of this study. This is in accordance with Galway Clinical Research Ethics Committee policy on data storage. (NUIG Ethics Data Protection Policy, 2012).

If you have any questions

If you have any questions or concerns about any aspect of this study, please feel free to contact the researcher, by email at orla.noonan@hse.ie or phone 0871322166. Thank you for taking the time to read this letter. I look forward to meeting you, should you decide to accept this invitation.

Thanking you,

Yours sincerely

Orla Noonan-Sweeney.

Appendix 4(C): Expression of Interest Form

After having read the information on the research study titled, Exploring the experience of living with an implantable cardiac defibrillator. A Heideggerian phenomenological study.

(Please indicate only one):

I would like to participate in this study:

I would not like to participate in this study:

If you want to participate, please include the following information:

Your name: _____

Your email address (if you have one):

Your phone number: _____

Appendix 5: Distress Protocol for Interviewees Experiencing Emotional Distress

In my clinical experience I have dealt with many individuals experiencing emotional distress and feel I would recognise this, if: as the interviewer I noticed any visual cues of emotional disruption, verbal or non-verbal such as withdrawal, upset, distressed, or verbal cues such as angry outbursts elevated tone of voice.

Before the beginning the interview, the interviewee will be shown a green disc, which will be placed on the table in front of him/her. This disc will act as one non-verbal way in which the interviewee can indicate that he/she would like to stop the interview while it is in progress; to stop the interview, the interviewee simply needs to turn the green disc over, so that its red underside is facing up, and the interview will end. The protocol below will be followed from step 3 onwards if the interview has been stopped because of emotional disruption.

If it comes to the attention of the researcher that the interviewee is emotionally disrupted, the following protocol will be enacted:

1. The researcher will ask the interviewee if they would like the interview to end, and the audio-tape to be turned off.
2. If the interviewee wishes to continue the interview, she will be asked if she would like the audio-tape to be turned off.
3. If the interviewee wishes to end the interview, the researcher will turn off the audio-tape, and ask the interviewee if she would like to talk about how she is feeling/why she is upset
4. If the interviewee wishes to talk about how she is feeling, the researcher will listen attentively, and provide neutral, confirming statements that validate their emotions and experience.
5. If the interviewee wishes not to talk about how she is feeling, this will be respected.
6. Before concluding the session, the interviewee will be asked how she is feeling, and if she will have a support network to talk with and to help her process her emotions.

7. If any person is distressed by the interview, I will refer to a specialist within this area.

An email has been forwarded to the psychology department informing them of the study and seeking their support if necessary. The Cardiology CNS LUH has also agreed to take any phone calls in relation to the device activation and medication concerns. All participants will be given the psychology department phone number a resource guide with websites including high-quality Irish and English support based support organizations.

8. Prior to leaving, the interviewer will again provide their email address and phone number for the interviewee to contact at a later date if they wish to access the researcher's support in finding community supports.

**Appendix 6: Declaration Statement of Confidentiality for
Transcriptionist**

This research project will focus the experience of living with an implantable (ICD).

As such, any information that you hear/read as a transcriptionist within this project must be kept entirely confidential and private and is not to be shared with any other individuals. This is to protect the safety and identity of the research participants, as well as to preserve the originality of the research project.

Statement of Confidentiality

As a transcriptionist I _____ understand that all of the data that I transcribe, must be kept completely private and confidential to the study.

I furthermore testify that I understand that any and all information obtained from my transcription of the interview data collected in this study will not be divulged under any circumstances.

Signed: _____ Date: _____

Name of Transcriptionist

Signed: _____ Date: _____

Appendix 7: Letter for Recruiting from Acute Hospital and Email to Cardiologist

My name is Orla Noonan Sweeney I am working as an Assistant Director of Nursing/Night service manager in Letterkenny University Hospital, Co Donegal. Prior to this appointment I was working for 15 years in the Cardiac rehabilitation department as Clinical Nurse Specialist. I am currently a student in the National University Hospital in Galway undertaking a PhD in Nursing Studies. As part of the PhD, I am conducting a research study “Exploring the experience of living with an implantable cardiac defibrillator. A Heideggerian phenomenological study”.

I am interested in speaking to individuals 18yrs or over who have an implantable defibrillator. I am hoping to recruit from acute hospitals. There is limited qualitative research available nationally or internationally. The findings of this study have the potential to inform practice. To participate in this study, I am asking hospitals to place information poster in the waiting areas of the cardiology clinic and cardiac investigation department inviting those eligible individuals to participate. Individuals eligible to participate must be aged 18 years or over with good English and have an ICD. I will also make available an information pack outlining in detail the purpose of the study, the researcher’s name and contact details, the reason for undertaking this study, what participating in the study will involve, how participants would be selected, the voluntary nature of participation, and the right to withdraw without compromise.

This is a qualitative study adopting a phenomenological approach. I and hope to begin the study in October 2018. Thank you for reading this letter.

Yours sincerely

Orla Noonan Sweeney (0871322166)

Appendix 8: Interview Question and Guide

Core question: I would like to ask you about your experience, can you tell me about it, what it like is for you to live with an implantable cardiac defibrillator (ICD).

General probes if required

- Can you tell me about your experience of being told that you needed an ICD?
- Can you tell me about your experience of any episode where it was activated?
- Can you tell me about your experiences of other people's reactions when they know you have an ICD?
- Can you tell me about how it affects your daily life?
- Can you tell me how your family responded?

Thank you for participating in this interview. Before we finish, is there anything else that you would like to add or say about your experience of living with an ICD?

Appendix 9: Researcher Safety Protocol

The researcher may be required to travel to many parts of Ireland in order to conduct interviews. It is impossible to foresee where participants will choose to be interviewed and therefore impossible to pre-arrange a neutral location for the interviews. Some may request that the interviews take place in their own home.

Entering the home of an unknown individual has the potential to possess some element of risk, the following Researcher Safety Protocol has been developed for any situations in which the principal investigator, Orla Noonan Sweeney is required to enter a non-public setting (i.e.. The participant's home) in order to conduct an interview.

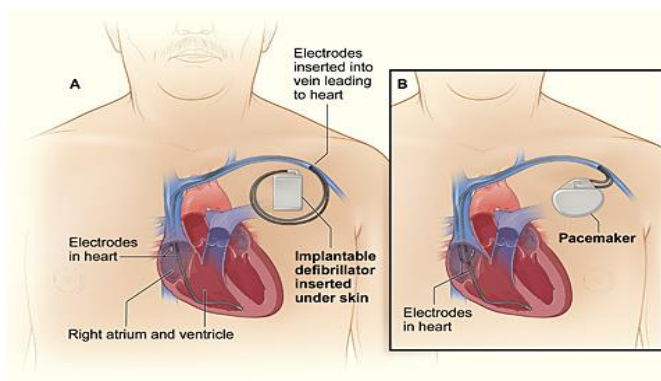
1. Prior the Interview, an email will be sent to the principal applicants' supervisor. This email will contain the address of the home in which the interview is to take place, the start time of the interview, and the end time of the interview.
2. Arrangements will be made prior to each such interview that, 15 minutes after the planned completion time of the interview, the principal applicant will call her supervisor to confirm that no harm has come to her.
3. In the event that the arranged individual does not receive said call after the passing of the arranged time, they will call the principal applicant to confirm that no harm has come to her.
4. If they are unable to reach the principal applicant, they will wait a further 30 minutes and try again if they have not been contacted by the principal applicant.
5. At this point, either the principal applicant's supervisor will contact local authorities and/or drive to the address at which the interview took place to investigate.
6. All emails with addresses of interviews that are sent and received as part of this protocol will be deleted on a daily basis, when all interviews for that day are complete and researcher safety is ensured.

Appendix 10: Invitation Poster

Exploring the experience of living with an Implantable Cardiac Defibrillator.

A research study conducted by Orla Noonan Sweeney as part of a Doctoral Study in NUI Galway

Do you have an Implantable Cardiac defibrillator?



Are you 18yrs or over?

Would you like to take part in a research study? If you are interested and would like to find out more, contact Orla on 0871322166 or email orla.noonan@hse.ie .

Appendix 11: Demographics Questions

- Age -----
- Sex -----
- Race/Ethnicity -----

- Relationship status -----

- Any dependants -----

- Length of time device implanted -----

- Reason for Implant -----

- Shock -----

- Driver -----

- Work status -----

- Contact details -----

Appendix 12(A): Email Request to Consultant Approval

From: Orla Noonan

Sent: 13/07/2017 14:00

To: [REDACTED]

Subject: PhD Study

Dear Dr [REDACTED]

I am a student in NUIG undertaking a PhD in nursing, a requirement for this is to undertake a research study of my choice. I have chosen to explore the experience of living with an implantable cardiac defibrillator (ICD). This is a qualitative study underpinned by Heidegger's interpretive phenomenology.

My aim is to explore the views of individuals 18yrs and over.

I currently work as a night manager in Letterkenny University Hospital, prior to this I worked as the co-ordinator in the Cardiac rehabilitation department for 15 years, thus my interest in Cardiology. I am aware that you have a special interest in Cardiology. I have also spoken with Antony Ryan who has agreed to support the study.

I am in the process of applying to the hospital ethics committee; however, I would appreciate your permission for access to patients before pursuing with my study. The study will involve interviewing individuals for approximately one hour that have an implantable cardiac defibrillator (ICD). I look forward to hearing from you. Thanking You. Kind regards
Orla.

Appendix 12(B): Email Request to Consultant Approval

Dear [REDACTED]

I am a student in NUIG undertaking a PhD in nursing, a requirement for this is to undertake a research study of my choice. I have chosen to explore the experience of living with an implantable cardiac defibrillator (ICD). This is a qualitative study underpinned by Heidegger's interpretive phenomenology.

My aim is to explore the views of individuals 18yrs and over. I currently work as a night manager in Letterkenny University Hospital, prior to this I worked as the co-ordinator in the Cardiac rehabilitation department for 15 years, thus my interest in Cardiology.

I am aware that I need to apply to the hospital ethics committee; however, I would appreciate your permission to access the patients before pursuing with my study. The study will involve interviewing individuals for approximately one hour that have an implantable cardiac defibrillator (ICD). I look forward to hearing from you. Thanking You.
Kind regards Orla.

Appendix 13(A): Consultant Approval

3:11 PM (13 minutes ago)

██████████
to me

Hi Orla,

I spoke to Dr ██████████ and discussed our previous telephone call. She is happy for the CRY centre to be a gateway for your proposed research study once the Tallaght ethics committee grant you approval. If you need any more help please contact me.

Kind regards,

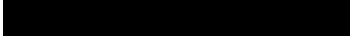
From: ██████████

Sent: 02 May 2017 10:52

To: orlanoonansweeney@gmail.com

Subject: RE: research study

Appendix 13(B): Consultant Approval

 To Orla Noonan/NWHB@nwhb
13/07/2017 14:05 cc
Subject RE: PhD Study

Hi
Delighted to assist in any way.
Please keep in touch

Sent from my Windows Phone

Appendix 13(C): Consultant Approval

████████████████████ To Orla Noonan/NWHB@NWHB
14/07/2017 15:52 cc
Subject Re: PhDLink

Dear Orla,

Thank you for your email.

You are welcome to use patient from our data base for your Phd.

yours sincerely

████████████████████
cardiologist

Appendix 14(A): Email Request to Support Groups

orla

Jul 13 (2 days ago)

noonansweeney <orlanoonansweeney@gmail.com>

████████████████████

|

Dear ██████████

Thank you for your advice in relation to my study. I was sorry to miss you at the Livewire evening. I hope you are feeling better.

I now have adapted the age range. I have chosen to explore the experience of living with an implantable cardiac defibrillator (ICD). This is a qualitative study underpinned by Heidegger's interpretive phenomenology. My aim now is to explore the views of individuals 18yrs and over. The study will involve interviewing individuals for approximately one hour that have an implantable cardiac defibrillator (ICD). I have decided to recruit from the hospital setting only. I am aware that there are no known risks associated with this method of research or interview, however I am is aware that the topic has the potential to cause emotive feelings, in the event of this occurring can I contact you with the participants consent to discuss further management or referral to your support group. I appreciate your advice. Thanking you

Yours sincerely

Orla Noonan Sweeney (08713222166)

Appendix 15: Email Request to Psychologist

Dear [REDACTED]

I am a student in NUIG undertaking a PhD in nursing, a requirement for this is to undertake a research study of my choice. I have chosen to explore the experience of living with an implantable cardiac defibrillator (ICD). This is a qualitative study underpinned by Heidegger's interpretive phenomenology.

My aim is to explore the views of individuals 18yrs and over.

I currently now working as a night manager in Letterkenny University Hospital, prior to this I worked as the Co-coordinator in the Cardiac rehabilitation department for 15 years, thus my interest in Cardiology. The study will involve interviewing individuals for approximately one hour that have an implantable cardiac defibrillator (ICD). There are no known risks associated with this method of research or interview; however, the researcher is aware that the topic has the potential to cause emotive feelings, in the event of this occurring can I contact the department to discuss further management. I appreciate your advice.

I look forward to hearing from you. Thanking You. Kind regards Orla.

Appendix 16: Evidence of NVivo 11

The experience of living with an ICD.nvp - NVivo Pro

FILE HOME CREATE DATA ANALYZE QUERY EXPLORE LAYOUT VIEW

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Sources

- Internals
- Externals
- Memos
- Framework Matrices

Internals

Name	Nodes	References	Created On	Created By	Modified On	Modified By
Orla Case P11		60	14/08/2018 12:22	ON	14/06/2019 00:15	ON
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Orla case P3		182	06/09/2018 11:13	ON	14/06/2019 00:08	ON
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Orla Case P2		76	05/07/2018 22:50	ON	14/06/2019 00:14	ON
Orla Case 10		39	06/07/2018 17:27	ON	14/06/2019 00:15	ON

ON 26 Items

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The experience of living with an ICD.nvp - NVivo Pro

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- Node Matrices

Sources

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Classifications

Collections

Queries

Reports

Maps

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Phase 1 -Naive Reading

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BEING UNABLE TO WORK		1	02/05/2018 23:47	ON	23/10/2018 21:47	ON
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BEING SURPRISED		1	03/05/2018 00:08	ON	29/07/2018 22:25	ON
WANTING TO ISOLATE MYSELF		1	03/05/2018 00:10	ON	23/10/2018 23:22	ON
BEING UNKNOWLEDGABLE		1	19/05/2018 19:29	ON	11/06/2018 21:51	ON
BEING OLDER		1	19/05/2018 20:19	ON	23/10/2018 23:22	ON
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BEING AWARE OF THE SCAR		1	11/06/2018 13:56	ON	23/10/2018 23:22	ON
HAVING A FEELING OF SINKING UNDERWATER		1	12/06/2018 09:54	ON	05/11/2018 19:40	ON
NOT TAKING IT SERIOUSLY		1	12/06/2018 09:54	ON	05/11/2018 19:40	ON
BEING UNAFFECTED		1	12/06/2018 09:54	ON	05/11/2018 19:40	ON
BEING UNABLE TO SIT EXAMS		1	12/06/2018 09:54	ON	23/10/2018 23:22	ON
BEING IMPACTING ON FRIENDS		1	12/06/2018 09:54	ON	24/10/2018 03:26	ON
THINKING I DONT NEED THIS THING		1	12/06/2018 09:54	ON	23/10/2018 23:22	ON
BEING OBSESSED		1	12/06/2018 09:54	ON	23/10/2018 23:22	ON

ON 687 Items

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The experience of living with an ICD.nvp - NVivo Pro

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- Phase 2 - Naive Understa
- Phase 3 - Depth Understa
- Cases
- Relationships
- Node Matrices

Sources

Nodes

Classifications

Collections

Queries

Reports

Maps

Folders

ON 373 Items

Phase 2 - Naive Understanding

Name	Sources	References	Created On	Created By	Modified On	Modified By
BEING ON A JOURNEY OF ACCEPTANCE		13	29	18/10/2018 13:53	ON	11/12/2018 01:20
BEING SCARY AT THE START		1	1	24/10/2018 18:31	ON	16/08/2018 14:16
BEING DIFFICULT AT THE START		1	1	24/10/2018 18:31	ON	09/09/2018 09:02
BEING UNSURE IF I NEEDED IT		1	2	11/12/2018 01:29	ON	14/07/2018 16:32
LEARNING TO ADAPT TO IT		1	1	11/12/2018 01:31	ON	22/09/2018 13:41
BEING AWARE IT HELPED ME		1	1	11/12/2018 01:33	ON	09/09/2018 11:02
AWARE I WOULDNT BE LIVING IF NOT FOR IT		1	2	11/12/2018 01:33	ON	22/09/2018 15:43
IT IS PROLONGING MY LIFE		1	1	11/12/2018 01:33	ON	22/09/2018 15:43
BEING POSITIVE		3	3	11/12/2018 01:36	ON	23/10/2018 22:11
BEING DIFFICULT TO ACCEPT INITIALLY		3	4	11/12/2018 01:36	ON	10/04/2019 21:53
BEING A SCARY EXPERIANCE		3	3	11/12/2018 01:36	ON	24/10/2018 01:52
BEING EASIER WITH TIME		4	6	24/10/2018 18:29	ON	23/10/2018 23:22
LOSING ONES IDENTITY		21	111	13/09/2018 18:02	ON	11/12/2018 17:05
BEING UNABLE TO EXERCISE		0	0	25/10/2018 00:04	ON	25/10/2018 00:04
RESTRICTED ARM MOVMENT		0	0	25/10/2018 00:05	ON	25/10/2018 00:05
HAVING A SCAR		0	0	25/10/2018 00:09	ON	25/10/2018 00:09
PALPATATIONS		0	0	25/10/2018 00:32	ON	25/10/2018 00:32
BEING PAINFUL		1	1	25/10/2018 00:27	ON	29/06/2019 17:48
BEING UNABLE TO SLEEP		3	4	24/10/2018 18:07	ON	05/11/2018 19:40
BEING UNABLE TO PERFORM CERTAIN ACTIVITIES		5	9	24/10/2018 18:07	ON	10/04/2019 22:04

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The experience of living with an ICD.nvp - NVivo Pro

FILE HOME CREATE DATA ANALYZE QUERY EXPLORE LAYOUT VIEW **Node Tools**

Coding Context Coding Excerpt Coding by Users Rich Text Coding Information

Coding Stripes Highlight Code Code In Vivo Spread Coding Uncode from This Node Query This Node Query Word Cloud Compare With Explore Diagram Visualize Node

Nodes Look for Search In Phase 2 - Naive Find Now Clear Advanced Find

Nodes

- Phase 1 - Naive Reading
- Phase 2 - Naive Understa
- Phase 3 - Depth Understa
- Cases
- Relationships
- Node Matrices

Sources

Nodes

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Maps

Folders

Phase 2 - Naive Understanding

Name	Source	Reference
BEING YOUNGER AND OLDER	9	20
BEING ON A JOURNEY OF ACCEPTANCE	13	29
BEING SCARY AT THE START	1	1
BEING DIFFICULT AT THE START	1	1
BEING UNSURE IF I NEEDED IT	1	2
LEARNING TO ADAPT TO IT	1	1
BEING AWARE IT HELPED ME	1	1
AWARE I WOULDNT BE LIVING IF NOT F	1	2
IT IS PROLONGING MY LIFE	1	1
BEING POSITIVE	3	3
BEING DIFFICULT TO ACCEPT INITIALLY	3	4
BEING A SCARY EXPERIANCE	3	3
BEING EASIER WITH TIME	4	6
LOSING ONES IDENTITY	21	111
BEING UNABLE TO EXERCISE	0	0
RESTRICTED ARM MOVMENT	0	0
HAVING A SCAR	0	0

Drag selection here to code to a new node

BEING PAINFUL BEING EASIER WITH TIME

Naw, now I'm grand and I started like exercising every day. I suppose just cause like the age I'm at and I kinda want to be fit, but naw now I'm grand like kinda that way, no fear of being by myself or anything. I do enjoy exercising now. Kinda after I got it in I was kinda a wee bit weary, oh should I get my heart rate up or whatever, you know I shouldn't do any strenuous activity, I kinda used that to my advantage in P.E. I was like "no I can't do that or whatever", whereas now naw I just go on like kinda.

<Internals\ORLA Case 5> - 2 references coded [11.23% Coverage]

Reference 1 - 8.14% Coverage

I would say it would have taken 3 - 4 years. It becomes part of you. You become to accept it, but before that you were always conscious, even coming out of the shower, you'd try to avoid mirrors so you wouldn't see it. Trying to fool yourself there was nothing there, in your own mind, and at the same time you know it's there. You come out of the shower and you are drying and you don't dry that side of your body, you are avoiding it. Small little things like that, and afraid to put certain soaps on it in case you might infect it. There's all this side of it too. It took a good, say 4 years, 3 - 4 years before I felt anyway confident with it at all. The feeling now, now I know it's there and I know on a few occasions it has been of benefit to my life, so I mean what I tell you is a lot different, it's now in a different light completely. Just now, very very positive whereas at the start it was extremely negative and scary.

In Nodes Code At Enter node name (CTRL+Q)

ON 373 Items Sources: 4 References: 6 Unfiltered 100%

05:05 PM 19/05/2020

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FILE HOME CREATE DATA ANALYZE QUERY EXPLORE LAYOUT VIEW

Go Refresh Open Properties Edit Paste Copy Merge Cut Copy Format Paragraph Styles Editing Proofing

Nodes Look for Search In Phase 3 - Depth Find Now Clear Advanced Find X

Phase 3 - Depth Understanding

Name	Sources	References	Created On	Created By	Modified On	Modified By
BEING TOWARDS DEATH		0	10/04/2019 20:36	ON	10/04/2019 20:36	ON
BEING TOWARDS THE FUTURE		1	10/04/2019 20:41	ON	10/04/2019 21:58	ON
BEING SHAPED BY PAST EXPERIENCE		2	10/04/2019 20:41	ON	30/06/2019 00:10	ON
BEING ROBBED OF ONES IDENTITY		4	10/04/2019 20:40	ON	29/06/2019 17:49	ON
BEING ON A JOURNEY OF ACCEPTANCE		0	10/04/2019 20:37	ON	10/04/2019 20:37	ON
BEING AWARE OF THE PASSAGE OF TIME		1	10/04/2019 20:43	ON	10/04/2019 20:57	ON
BEING ACCEPTING		2	10/04/2019 20:43	ON	10/04/2019 21:56	ON
BEING A STRUGGLE WITH EMOTIONS		3	10/04/2019 20:42	ON	10/04/2019 21:55	ON
BEING SUPPORTED AND INFORMED		0	10/04/2019 20:38	ON	10/04/2019 20:38	ON
BEING FINANCIALLY BURDENED		2	10/04/2019 20:44	ON	10/04/2019 21:53	ON
BEING SUPPORTED BY OTHERS		3	10/04/2019 20:43	ON	10/04/2019 22:05	ON
BEING INFORMED BY SERVICES		3	10/04/2019 20:44	ON	10/04/2019 22:08	ON

ON 12 Items

EN 04:35 PM 19/05/2020

The experience of living with an ICD.nvp - NVivo Pro

FILE HOME CREATE DATA ANALYZE QUERY EXPLORE LAYOUT VIEW **Node Tools**

Coding Context Coding Excerpt Coding by Users Rich Text Coding Information

Coding Stripes Highlight Code Spread Coding Uncode from This Node Query This Node Query Word Cloud Compare With Explore Diagram Visualize Node

Nodes Look for Search In Phase 2 - Naive Find Now Clear Advanced Find

Nodes

- Phase 1 - Naive Reading
- Phase 2 - Naive Understa
- Phase 3 - Depth Understa
- Cases
- Relationships
- Node Matrices

Sources

Nodes

Classifications

Collections

Queries

Reports

Maps

Folders

Phase 2 - Naive Understanding

Name	Source	Reference
BEING EASIER WITH TIME	4	6
LOSING ONES IDENTITY	21	111
BEING UNABLE TO EXERCISE	0	0
RESTRICTED ARM MOVMENT	0	0
HAVING A SCAR	0	0
PALPATATIONS	0	0
BEING PAINFUL	1	1
BEING UNABLE TO SLEEP	3	4
BEING UNABLE TO PERFORM CERTAIN A	5	9
BEING UNABLE TO DRIVE	9	19
BEING ON A JOURNEY OF ACCEPTANCE	13	39
BEING TOWARDS DEATH	14	37

Drag selection here to code to a new node

BEING PAINFUL BEING EASIER WITH TIME **BEING TOWARDS DEATH**

voltage. So I don't feel it I'm back (Laugh). So I have never felt it. I had J.... The neighbour the first time it happened in the kitchen and she said my body did give a sudden jerk. Which must have been it working I guess. Other than that I was just out for seconds not even ... so I was.

References 2-3 - 6.84% Coverage

When I was up at one of my check-ups I asked a question what would happened if I actually died would it just keep shocking me until the battery ran out . She explained that what it does, I probably got the figures wrong it well shock every two seconds six times and then it will wait a couple of minutes and do the whole thing again. Then it will go through this sequence 4 times. That's the list of what she told me.

Reference 4 - 10.68% Coverage

There is something I can tell you they tried to resuscitate me at the beach and there was people from midlands worked on another 20 mins. Then I was in the coma, So I was transferred then I don't remember anything about that but you could say it was quite easy to Die. One minute and you don't even know your gone to the next minute.

Just to clarify how does that affect you knowing you could die so easy.





























































Doesn't bother me in the least funny enough. I am on borrowed time. My friend said he was putting

In Nodes Code At Enter node name (CTRL+Q)

ON 373 Items Sources: 14 References: 37 Unfiltered

05:10 PM 19/05/2020

Appendix 17: Evidence of Literature Review Search

Search ID#	Search Terms	Search Options	Actions
<input type="checkbox"/> S20	 S17 AND S18 AND S19	Search modes - Boolean/Phrase	 View Results (18)  View
<input type="checkbox"/> S19	 S15 OR S16	Search modes - Boolean/Phrase	 View Results (185,849)  View
<input type="checkbox"/> S18	 S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14	Search modes - Boolean/Phrase	 View Results (234,288)  View
<input type="checkbox"/> S17	 S2 OR S3	Search modes - Boolean/Phrase	 View Results (89)  View
<input type="checkbox"/> S16	 CARDIAC PATIENTS	Search modes - Boolean/Phrase	 View Results (500)  View
<input type="checkbox"/> S15	 PATIENTS	Search modes - Boolean/Phrase	 View Results (185,849)  View
<input type="checkbox"/> S14	 ACCEPTANCE	Search modes - Boolean/Phrase	 View Results (7,122)  View
<input type="checkbox"/> S13	 SURVIV*	Search modes - Boolean/Phrase	 View Results (22,975)  View
<input type="checkbox"/> S12	 LIVING	Search modes - Boolean/Phrase	 View Results (26,673)  View
<input type="checkbox"/> S11	 HEALTH BELIEFS	Search modes - Boolean/Phrase	 View Results (542)  View
<input type="checkbox"/> S10	 REACTION	Search modes - Boolean/Phrase	 View Results (27,879)  View
<input type="checkbox"/> S9	 PERSPECTIVE	Search modes - Boolean/Phrase	 View Results (35,969)  View
<input type="checkbox"/> S8	 OPINION	Search modes - Boolean/Phrase	 View Results (23,263)  View
<input type="checkbox"/> S7	 BELIEF	Search modes - Boolean/Phrase	 View Results (20,472)  View
<input type="checkbox"/> S6	 ATTITUDE TO ILLNESS	Search modes - Boolean/Phrase	 View Results (317)  View
<input type="checkbox"/> S5	 ATTITUDE	Search modes - Boolean/Phrase	 View Results (50,449)  View
<input type="checkbox"/> S4	 experience	Search modes - Boolean/Phrase	 View Results (74,632)  View
<input type="checkbox"/> S3	 implantable cardioverter defibrillator	Search modes - Boolean/Phrase	 View Results (84)  View
<input type="checkbox"/> S2	 implantable defibrillator	Search modes - Boolean/Phrase	 View Results (61)  View
<input type="checkbox"/> S1	 cardiac implantable defibrillator	Search modes - Boolean/Phrase	 View Results (0)  View

	IMPLANTABLE DEFIBRILLATORS	Select a Field (optional) ▾
AND ▾	EXPERIENCE	Select a Field (optional) ▾
AND ▾	LIVING	Select a Field (optional) ▾
AND ▾	PATIENTS	Select a Field (optional) ▾
NOT ▾	PACEMAKERS	Select a Field (optional) ▾
NOT ▾	subcutaneous	Select a Field (optional) ▾
NOT ▾	resynchronisation therapy	Select a Field (optional) ▾

[Basic Search](#) [Advanced Search](#) [Search History](#) ▶

Search Results: 1 - 10 of 66

Database X

<input type="checkbox"/> Name ↕	Hit Count ▾
<input checked="" type="checkbox"/> All Databases	
<input type="checkbox"/> Academic Search Complete	809
<input type="checkbox"/> CINAHL Complete	659
<input type="checkbox"/> UK & Ireland Reference Centre	67
<input type="checkbox"/> General Science Full Text (H.W. Wilson)	41
<input type="checkbox"/> Psychology and Behavioral Sciences Collection	12
<input type="checkbox"/> SocINDEX with Full Text	9
<input type="checkbox"/> AgeLine	4
<input type="checkbox"/> Social Sciences Full Text (H.W. Wilson)	4

Update
Cancel

Appendix 18: Evidence of Manual Coding

PHYSICAL	PSYCHOLOGICAL	SOCIAL ASPECT
<p>Being painful</p> <p>Being scared it might fall out</p> <p>Being out of breath</p> <p>Being dizzy</p> <p>Being a strange sensation</p> <p>Having palpitations</p> <p>Uncomfortable with arm movement</p> <p>The feeling of a brick on your chest</p> <p>Being tired</p>	<p>Everything was coming at me</p> <p>Like a panic attack</p> <p>Being devastated</p> <p>Being in denial</p> <p>Affected mentally</p> <p>Unable to sleep</p> <p>Devastated</p> <p>Nervous</p> <p>Guilty</p> <p>Shocked</p> <p>Afraid to let water near it</p> <p>My heart was broken</p> <p>Feeling anxious</p>	<p>Going through the airport</p> <p>Being scanned at the airport</p> <p>Living in the country</p> <p>Being unable to enjoy their new home</p> <p>Being a factor at work</p> <p>Wanting my independence back</p> <p>Being unable to drive</p>
FINANCIAL BURDON	TIME	SHAPED BY PAST EXPERIENCE
<p>Being a lorry driver</p> <p>Losing my HGV licence</p> <p>Getting a new job</p> <p>Being unable to drive</p> <p>Losing my livelihood</p> <p>Unqualified to do anything else</p> <p>Having to go to Dublin every six months</p> <p>Being redeployed</p> <p>Impacting financially</p>	<p>Being easier with time</p> <p>Being scary at the start</p> <p>A slow recovery</p> <p>Being a bit uncomfortable at the beginning.</p>	<p>Being life changing</p> <p>Having a shock could change your views</p> <p>Never wanting to put her family in that position again</p> <p>Waiting for a shock</p> <p>Being a horrible feeling</p>

<p>Awareness</p> <p>Being aware of public lack of understanding</p> <p>Taken back by people's comments</p> <p>Having to explain to people at the airport</p> <p>Being treated differently</p> <p>Being expected to return to normal</p> <p>Being told to think about retiring</p>	<p>INFORMATION</p> <p>Being given some literature</p> <p>Not knowing much about it</p> <p>Aware of the lack of information</p> <p>Never really explained</p> <p>Unsure what to expect</p> <p>Dissatisfied with the follow up care</p> <p>Emphasis is on keeping you alive</p> <p>Given a lecture by the nurse</p> <p>Shown an ICD by the Doctor</p>	<p>YOUNGER AND OLDER</p> <p>Interfering with relationships</p> <p>Being pregnant</p> <p>Being unable to sit school exams</p> <p>Aware of the scare</p> <p>Being retired</p> <p>Being a mother with young children</p>
<p>SUPPORT</p> <p>Being dismissed medically</p> <p>Being on a home monitor</p> <p>Good family support</p> <p>Making contact with someone in a similar situation</p> <p>No support groups in Donegal</p> <p>Being referred to cardiac rehabilitation</p> <p>Trusting the</p>	<p>BEING TOWARDS DEATH</p> <p>A major event</p> <p>Like an out of body experience</p> <p>Unpleasant feeling but necessary</p> <p>A feeling of being hit by a sledge hammer</p> <p>A feeling of sinking underwater</p> <p>Being alone</p> <p>Having a seizure</p> <p>Being resuscitated Afraid of dying</p>	<p>ACCEPTANCE</p> <p>Being determined</p> <p>Questioned her purpose in life</p> <p>Aware this device was going to save your life</p> <p>Having to adapt</p> <p>Not wanting it</p> <p>Psychologically hard to accept</p> <p>Developing coping mechanisms</p> <p>Being a backup plan</p>

<p>cardiologist Brilliant staff Access to specialist support in the unit when needed Referred to psychologist Joined the heart failure support group Joined the men's shed</p>	<p>On borrowed time Faith in God</p>	
<p>Losing identity Being restricted with clothes I wear Being conscious of the scar Thinking there was something abnormal in her body Only allowed to walk or light jog for the rest of my life Being unable to do contact sports Being unable to lift</p>		

Appendix19: Email to the Director of Nursing

Dear [REDACTED]

I am a student in NUIG undertaking a PhD in nursing, a requirement for this is to undertake a research study of my choice. I have chosen to explore the experience of living with an implantable cardiac defibrillator (ICD). This is a qualitative study underpinned by Heidegger's interpretive phenomenology. My aim is to explore the views of individuals 18yrs and over.

I am aware that I need to apply to the hospital ethics committee; however, I would appreciate your permission to access the patients before pursuing with my study. The study would involve interviewing individuals for approximately one hour that have an implantable cardiac defibrillator (ICD). I look forward to hearing from you. Thanking You. Kind regards Orla Noonan Sweeney.

