

**Women's experiences of living
with an implantable cardioverter
defibrillator**

A thesis presented in partial fulfilment of the requirements for the degree of

Master of Nursing

At the Eastern Institute of Technology, Taradale, New Zealand

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2016

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Abstract

Implantable cardioverter defibrillators (ICDs) are used to treat lethal arrhythmias in patients identified as at risk of sudden cardiac death and can form an additional part of a cardiac resynchronisation therapy device (CRT) which is used for the treatment of heart failure. These cardiac devices are becoming increasingly utilized within New Zealand and internationally.

Quantitative research has shown an increased risk of psychological harm and reduced quality of life with an ICD, however, evolving ICD technology may affect current experiences. There is no qualitative research on New Zealanders with ICDs and little qualitative research on women's experiences with an ICD, which this study aimed to rectify.

This research used qualitative methodology to explore the experiences of women living with an ICD for more than six months. Semi structured individual interviews were conducted with 14 women to capture a range of experiences of New Zealand women living with an ICD. ICD indication, age, ethnicity, employment status and household composition were varied, with four women continuing to raise dependent children since their ICD implant.

A wealth of information was shared by the participants. Data analysis identified four main themes for reporting: the effect of antecedent events leading to the ICD implant; the physical realities and practicalities of the ICD device; the positive value placed on interpersonal relationships; and the impact of contemplating mortality.

Discussion focused on issues relevant to nursing that were identified by the women as having significance to their experience. Discussion topics include experiences of discharge following an ICD implant, engaging in physical activity, the impact of driving restrictions, the impact of being a mother, depression and emotional adjustment and considerations concerning end of life care.

These findings provide a detailed perspective of the experiences and issues facing New Zealand women living with an ICD. Recommendations could be used by nurses to provide more targeted information and support to women receiving ICDs.

CONTENTS

Declaration	i
Abstract	ii
Glossary	viii
CHAPTER ONE – Introduction	1
Purpose of the Research	1
Who has an ICD?	1
What an is an ICD?	1
An ICD as part of another cardiac device (CRT-D)	2
How ICD/CRT-Ds are implanted	2
ICD indication	3
CRT-D indication	3
Clinical benefit of an ICD	4
Clinical benefit of a CRT device	4
ICD prevalence	5
CRT prevalence	5
The researcher’s interest - beyond clinical benefit	6
Significance of the research	6
Overview of the thesis	6
CHAPTER TWO – Literature Review	8
Literature review structure	8
Original research question	8
Purpose of the literature review	8
Literature review search strategy	8
Quantitative studies	8
Psychosocial function	8
Anxiety and depression	9
Post-Traumatic Stress Disorder (PTSD)	10
Review of study methodology	11
Qualitative studies	12
Limitations of literature reviewed	15
Changing technology	15
Different cultural backgrounds	15

Benefit of further research	17
Refocused research question	17
Terminology choice	17
CHAPTER THREE – Methodology	18
Methodology	18
Ethical approvals	19
Ethical considerations	20
Research participants	22
Recruitment	22
Support people/third party presence	23
Data collection method	24
Data Analysis	26
Trustworthiness	26
Considerations for Māori	27
CHAPTER FOUR – Results	29
Introduction	29
Participant characteristics	29
Participant age and time living with an ICD	29
Ethnicity	30
Family structure	30
Employment	30
Driving status	30
Defibrillator indication	31
Device type	32
Device activation	32
Effect of antecedent events	33
Physical device realities and practicalities	35
Procedure experience	35
Experience of discharge home	38
Changed physical condition post ICD/CRT-D	40
Loosing condition	40
Gaining physical condition	43
Physical awareness of the device	44
Initially painful	44
Persisting physical sensations/pain around ICD	44

Associated pain	46
Consciousness of ICD presence	47
Physical consciousness	47
Self-consciousness	48
Normality - loss of abnormal physical sensation	50
Physical activity	50
Coping with medically recommended restrictions post an ICD	50
Activities of daily living	53
Exercise: activity beyond that of daily living	54
Travel	57
Bedside monitor	60
Device activation: shocking	64
Complications with an ICD device	70
Effect on other healthcare experiences	74
Genetics: effect on health experience of family	79
Experiences around driving	81
Legal requirement	81
Complying or not or early permission	82
Issues with driving limits	84
Issues with public transport	86
Difficulties planning activities	88
Driving again	89
Fear that it will return	89
Positive value placed on interpersonal relationships	90
Relationship with partners	90
Relationship with parents	93
Relationship with independent adult children	94
Relationships with dependent children	96
Emotional impact of the cardiac arrest and ICD on the relationship	97
Practical care of children	98
Just need to get on	99
Importance of having the time with your children	99
Age of children and support they provide	100
Relationships at work	101
Friends and peers	103
Relationships with healthcare staff	106

Wider community interpersonal interaction	109
Contemplating mortality	110
The meaning of 'if' when talking about death...	110
Death as suddenly nothing	111
The benefit of a sudden death by cardiac arrest	113
Emotions and attitudes	114
Uncertainty verses confidence in the ICD	114
Depression and dwelling on death	115
Avoidance and fear	118
Carrying on	119
Acceptance, facing mortality	119
Counting your blessings and being thankful	120
Enjoying life	121
Re-prioritising	121
Planning for death	122
Locality	122
Practically planning for death	123
Palliative care	124
Ending it all	125
Summary	126
CHAPTER FIVE – Discussion	127
Introduction	127
The discharge experience	127
Physical activity	133
Benefits of physical activity	133
Guidelines on participation in physical activity	133
Reduction or avoidance of activity	135
Concerns around arrhythmias, device damage as related to exercise	137
Limited by underlying condition	138
Benefits of exercise with an ICD	138
The impact of the driving restrictions	140
The impact of being a mother	146
Depression and emotional adjustment	150
Discussion on end of life care	154

Nursing and peer support for ICD recipients	159
Summary	163
CHAPTER SIX – Conclusion	164
Limitations	166
Strengths	166
Recommendations	167
Recommendations for further investigation	167
Recommendations for nursing practice	167
References	170
APPENDICES	
Appendix 1: Letter of introduction to potential participants	185
Appendix 2: Information for Research Participants	186
Appendix 3: Consent form	188
Appendix 4: Māori Health Service letter of support	189
Appendix 5: Eastern Institute of Technology research and ethics approval	190
Appendix 6: Response to EIT research and ethics committee	191
Appendix 7: Institutional approval	192
Appendix 8: Interview Guide	193

Glossary

Aborted sudden cardiac death: a cardiac arrest that was successfully resuscitated.

Anti-Tachycardia Pacing (ATP): low energy electrical impulses to promote a normal heartbeat by pacing a little faster than the intrinsic rhythm and then slowing down to a more normal rate.

Appropriate shock: a shock delivered appropriately by an ICD to attempt to terminate a potentially lethal ventricular arrhythmia.

Atrial Fibrillation (AF): a cardiac electrical arrhythmia, characterised by disorganised electrical activity in the atria, often with a rapid rate. The atria do not contract in an organised fashion, resulting in reduced stroke volume.

AV junction: an area that connects the electrical conduction between the atria and ventricles.

Cardiac Resynchronization Therapy with Defibrillator (CRT-D): a cardiac device that provided bi-ventricular pacing to co-ordinated ventricular contraction and improve cardiac output.

Cardio Pulmonary Resuscitation CPR: basic emergency procedure for life support, consisting of artificial respiration and external cardiac compressions, in an effort to maintain circulation and oxygenation during cardiac arrest.

Community cardiac arrest: cardiac arrest that occurs in the community rather than in hospital, otherwise referred to as an out of hospital cardiac arrest (OHCA).

Defibrillation: delivery of an electric shock to the precordium (if external) or heart (if internal), aiming to terminate lethal ventricular arrhythmias, although it is also used for reverting AF.

Device activation/therapy: treatment with a cardiac device, ICD, CRT-D or PPM, either defibrillation or ATP.

Device: in this context will refer to ICDs, CRT-Ds and PPMs.

Ejection Fraction (EF): the proportion of blood ejected with each ventricular contraction as compared with the total volume in the ventricles, see also LVEF

External defibrillation: defibrillation from an external source not an internal cardiac device, most often an external defibrillator and transcutaneous pads.

General Practitioner (GP): a family practice physician

Implantable Cardioverter Defibrillator (ICD): Implanted cardiac device with electrodes to the heart capable of monitoring the intrinsic rhythm of the heart and delivering ATP and defibrillation if lethal arrhythmias are detected.

Inappropriate shock: a shock delivered without an appropriate lethal ventricular arrhythmia trigger.

In-hospital cardiac arrest: cardiac arrest that occurs while patient in hospital.

Ischemic Heart Disease (IHD): a pathological condition of the coronary arteries resulting in reduced blood flow to the myocardium.

Left Bundle Branch Block (LBBB): abnormal electrical conduction down the ventricles through the bundle branches, the left bundle is delayed resulting in slower contraction of the left ventricle.

Lethal (ventricular) arrhythmias: arrhythmias arising from the ventricles which can result in death, specifically Ventricular Tachycardia (VT) and Ventricular Fibrillation (VF).

Myocardial Infarct (MI): necrosis of a portion of the myocardium caused by reduced blood flow, typically from a clot or atherosclerosis. Colloquially referred to as a heart attack.

Non-lethal arrhythmias: heart rhythms other than normal sinus rhythm than are compatible with life.

Occupational Therapist (OT): an allied health professional, who is concerned with evaluating, diagnosing and treating people's ability to manage the activities of daily living.

Out of hospital cardiac arrest (OHCA): cardiac arrest that does not occur in hospital, also colloquially referred to as a community cardiac arrest.

Permanent Pacemaker (PPM): an implanted cardiac device that stimulate the heart with low voltage electrical impulses, aiming to increase the heart rate above a predetermined minimum.

Primary prevention ICD/indication: refers to those with an identified issue that increases this risk of cardiac arrest. This includes those with known structural or electrical pathway defects, like congenital heart disease, cardiomyopathy, long QT syndrome and Brugada syndrome as well as some classes of heart failure.

Secondary indication ICD/indication: refers to those who have already survived a sudden cardiac arrest or life threatening arrhythmia.

Shock therapy: activation of the defibrillator function of an ICD/CRT-D.

Shocks/fired/discharged/activated: used interchangeably by the participants regarding the defibrillation action of their ICD.

Sudden cardiac death (SCD): cardiac arrest

Type D personality: is characterised by the tendency to experience negative emotions across time and to inhibit these emotions.

Ventricular arrhythmia storms: three or more sustained episodes of VT or VF or appropriate implantable cardioverter-defibrillator (ICD) shocks during a 24-hour period.

CHAPTER ONE

Introduction

Purpose of the Research

The purpose of this research was to provide a better understanding of how having an implantable cardioverter defibrillator (ICD) impacts on women's lives in New Zealand. The knowledge and information gained from this research may contribute to existing national and international understanding of the experiences for women of living with an ICD and could be used by health care services to provide more appropriate and relevant support for this population.

The research question is,

What are women's experiences of living with an implantable cardioverter defibrillator?

The research aims to explore the broad experiences of women living with ICDs, examining how it affects them physically, socially and emotionally. In doing so, the research aims to identify any issues, positive or negative, the women faced as well as obstacles encountered and sources of strength they utilized in living with an ICD.

Who has an ICD?

Individuals identified as having an increased risk of sudden cardiac arrest (SCA).

What is an ICD?

An implantable cardioverter defibrillator (ICD) is a programmable device consisting of a generator and battery pack, with electrodes or leads threading into the heart. It is used to monitor and help regulate potentially fast and life-threatening electrical problems with the heart, specifically those in the lower chambers; ventricular tachycardia (VT) and ventricular fibrillation (VF). A modern ICD can respond to VF or VT with either anti-tachycardia pacing (ATP) consisting of low energy impulses to promote a normal heartbeat by pacing a little faster than the intrinsic rhythm and then slowing down to a more normal rate, or with shock therapy producing high energy impulses to promote defibrillation and prevent SCA. Additionally, it is capable of pacing for bradycardia and will record and store information about the heart rhythm and ICD therapies delivered Larsen, De Silva, Harding, Woodcock, and Lever (2010); (van Welsenes et al., 2011). Early ICDs had basic rhythm recognition software, were only capable of defibrillation, were more likely to shock and to shock inappropriately when not required (van Welsenes et al., 2011).

An ICD as part of another cardiac device (CRT-D)

An ICD can be a stand-alone cardiac device, or an additional function in a cardiac resynchronisation therapy (CRT) device. A CRT device works as a continuous bi-ventricular pacemaker to co-ordinate the chambers of the heart. Conduction delays through the ventricles lead to asynchronous contraction of left ventricular (LV) wall regions (ventricular dyssynchrony), impairing cardiac efficiency, reducing stroke volume and systolic blood pressure. These impairments promote adverse LV remodelling, worsening the cardiac function. Restoring ventricular synchrony can improve heart function and induce positive ventricular remodelling, although the effectiveness of this can vary between recipients (Brignole et al., 2013; van Welsenes et al., 2011).

The CRT function provides ongoing support and intervention to the cardiac rhythm with the aim of improving cardiac function. These improvements should result in feelings of physical improvement. Whereas, the defibrillator function in a device monitors cardiac rhythm, only intervening if a lethal arrhythmia is detected, offering no support to cardiac pump function and therefore no continuous improvement physically in recipients. A CRT device with a defibrillator function, is a CRT-D, with both functions remaining independently programmable within the same physical device (Brignole et al., 2013).

How ICD/CRT-Ds are implanted

The first generation ICDs required open chest surgery, with a thoracotomy, to place the electrodes, as they used an epicardial lead system, with the generator and battery pack being implanted abdominally. These early ICDs were placed in an operating theatre under full anaesthetic, but now implantation is able to be performed in an electrophysiology lab under conscious sedation, as current devices use trans-venous placement of an endocardial lead system (van Welsenes et al., 2011). The device is now usually inserted subcutaneously, by a subclavian access, on the upper portion of the pectoralis major muscle, typically on the left side. The subclavian scar and visibility of the device outline can have an aesthetic impact on ICD recipients, especially for young women. Women can also report irritation from seat belts, bra and purse straps (Persichetti et al., 2014). Therefore alternative ICD placement, particularly in women, is being trialled in some countries, including sub-mammary placement and sub-pectoral (Giudici, Carlson, Krupa, Meierbachtol, & Vanwhy, 2010; Persichetti et al., 2014). Totally subcutaneous ICD systems are also being trialled (Mithani et al., 2016).

ICD indication

The individual reason for receiving an ICD can be assigned to one of two main categories. Either secondary prevention for those who have already survived a sudden cardiac arrest or life threatening arrhythmia, or primary prevention for those with an identified issue that increases this risk. Primary prevention patients have not yet had a cardiac arrest and include those with known structural or electrical pathway defects, like congenital heart disease, cardiomyopathy, long QT syndrome and Brugada syndrome (W. Smith, 2010). It is recommended that primary ICD placement is also considered for those with class II to III heart failure (HF) on the New York Heart Failure (NYHF) scale, provided they are undergoing optimal medical therapy and have a reasonable expectation of survival of more than a year with good functional status (National Heart Foundation of New Zealand, 2009). However, the New Zealand ICD guidelines restrict device placement to those aged seventy five years or less with a likelihood of survival greater than eighteen months from other co-morbidities. These restrictions may not occur in all countries, but are formed with available evidence for pragmatic reasons, while considering the economic needs of competing health issues (W. Smith, 2010), as New Zealand has a predominantly publically funded, universal coverage health system with services provided by public, private and nongovernment organisations (Cumming et al., 2014).

CRT-D indication

CRT devices are used to correct cardiac dys-synchrony, which is a complex and multifaceted problem. New Zealand guidelines for CRT placement include NYHF class III patients with a left ventricular ejection fraction (LVEF) of less than 35% after being on optimal medical treatment for more than six weeks, with a left bundle branch block (LBBB) and ideally in sinus rhythm. New Zealand guidelines restrict device placement to individuals without major or life limiting co-morbidities (W. Smith, 2010). With an uncontrolled heart rate, ablation to the atrioventricular (AV) junction and pacing with CRT, can be used to manage atrial fibrillation (AF) and improve symptoms (Brignole et al., 2013).

The theoretical benefit of adding a defibrillator function to a CRT device is clearly to reduce the risk of cardiac arrest in a population that often meets the criteria for an ICD anyway, however, the actual benefit is less clear from trial data. A meta-analysis by Lam and Owen (2007) found that controlled trial evidence is insufficient to show the superiority of combined CRT-D therapy over CRT alone in patients with left ventricular impairment. Al-Majed, McAlister, Bakal, and Ezekowitz (2011) agreed, with their meta-analysis of published trials on CRT showing

the mortality benefit of CRT was largely driven by a reduction in HF-related mortality, however, the CRT and control groups did not differ significantly in their risk for sudden cardiac death. The risk reduction in sudden death after a CRT is probably related to positive cardiac remodelling (Brignole et al., 2013). Therefore the New Zealand guidelines on ICD/CRT placement recommend that choosing a CRT-D device is best determined on an individual basis by patients and their doctors (W. Smith, 2010).

Clinical benefit of an ICD

Consensus on the clinical benefit of secondary ICD implantation was obtained via three major studies in the 1990s, collectively the AVID (Antiarrhythmic Verses Implantable Defibrillators), CASH (Cardiac Arrest Study Hamburg) and CIDS (Canadian Implantable Defibrillator Study). A meta-analysis of these studies reported an significant all-cause mortality reduction of 28% in the ICD treated group (van Welsenes et al., 2011).

Primary prevention ICD trials occurred increasingly after benefit was shown with secondary prevention ICDs. A meta-analysis of ten primary prevention trials showed a 25% all-cause mortality risk reduction in ICD patients, leading to expanded international guidelines on indications for ICD and increasing numbers of primary prevention patients (W. Smith, 2010; van Welsenes et al., 2011).

Clinical benefit of a CRT device

HF prognosis is generally poor, early studies in the 1980's found a life expectancy of three and a half years, whereas with contemporary pharmacological therapy and CRT therapy this has increased to eight years (Brignole et al., 2013). CRT devices are implanted in part to improve the functional status of patients with CHF (Kramer, Jones, Rogers, Mitchell, & Reynolds, 2015). Kramer et al. (2015) found that physical activity following CRT-D implantation increases on average over 30 minutes per day and survival was markedly improved in patients who demonstrated improved activity levels.

CRT-induced improvement in dys-synchrony is associated with significant clinical benefit, with a significantly lower incidence and risk of HF/death (Goldenberg et al., 2011; Kutiyifa et al., 2013). The COMPANION trial in 2003 randomized patients into optimal medical therapy and CRT or CRT-D plus optimal medical therapy, showing that CRT-D reduces mortality by 36% compared to standard therapy. The MADIT-CRT and CARE studies have also demonstrated significant mortality benefits with CRT-D (W. Smith, 2010; van Welsenes et al., 2011). Although women were underrepresented in CRT-D trials, analysis has shown that in some clinical sub-categories with CRT-D women benefit more than men, with a 79% reduction

in HF or death, where men showed no significant difference (Zusterzeel, Selzman, Sanders, & et al., 2014).

ICD prevalence

ICD use in New Zealand and internationally is rising but in 2013 New Zealand's ICD implant rate of 95/million population remained significantly lower than Australia at 167/million (Mond & Crozier, 2015). This implantation rate had risen since 2008, when New Zealand's rate was 41/million, significantly lower than in the United States of America (USA) (577/million), Australia (145/million) and Western Europe (140/million), despite similar rates of cardiovascular disease (Burgess et al., 2011; D. Wilson et al., 2012). While the numbers of ICDs are increasing in New Zealand, Burgess et al. (2011) found that twelve percent of adult patients who presented to the Wellington regional ambulance service with a cardiac arrest (without a clearly non-cardiac etiology) met the indication for an ICD in their medical history but had not been referred. This retrospective audit supports the suggestion that ICDs are potentially under-utilised in at least this area of New Zealand. Variations in implantation rates across district health boards in New Zealand also suggest inequitable geographical access (D. Wilson et al., 2012). There are also major differences in ICD utilization between men and women. The majority of ICDs being implanted in men age ≥ 65 years. USA data has found implantation of ICDs was two and a half times more common in men than in women (402 per million vs 163 per million) as during 2011, only 29.7% of ICDs were implanted in women, which they believe is reflective of international trends (Patel et al., 2016). Internationally, 33-50% of ICDs are implant in patients over 70 years old, however, in New Zealand only 25% are over 70 years old (Larsen et al., 2013). Within New Zealand an audit of ICDs implanted between 2000 and 2007 found 73% were for secondary prevention, although during this time frame the number of primary prevention devices were noted to increase, in line with international trends (Larsen et al., 2010). By 2012 increasing primary prevention rates meant only 54% of ICDs were for secondary prevention (Larsen et al.).

CRT prevalence

About two percent of the adult population in developed countries have HF and about half will have a reduced LVEF. Using current research, around five to ten percent of patients with HF are indicated for CRT, which leads to estimates that around 400 patients per million population per year might be suitable for CRT. CRT implantation in Western and Central Europe was 140 units per million population, in 2011, of which 107 units were CRT-D and 33 were solely CRT. This rate has been steadily rising (Brignole et al., 2013). As with ICDs, women are less likely

to receive a CRT-D device (Zusterzeel et al., 2014). In New Zealand CRT devices were first implanted in 2003, these implantation rates are also rising, accounting for less than five percent of newly implanted devices in 2007 (Larsen et al., 2010) but 15% of new devices implanted in 2012 (Larsen et al., 2013).

The researcher's interest - beyond clinical benefit

Assessment of clinical benefit looks narrowly at mortality and morbidity rates, but not in more depth at quality of living and the burden of morbidity, areas that are of particular interest to me. Being a New Zealand cardiology nurse and having a family member living with an ICD, I have observed differing psychosocial responses to ICD device therapy. In these roles I have also discussed a range of issues, from emotional to practical, encountered with ICD recipients, both on insertion and after device activation or shock. I am interested in people's perceptions of their ICD, their experiences of living with an ICD and what issues they have encountered. I also wondered whether their indication for implantation and device activation altered their perceptions and experiences, issues the literature review will explore in more detail.

Significance of the research

Only one study on psychosocial factors, involving 46 ICD recipients, has been conducted in New Zealand. This study was quantitative, which limits responses to set questions and does not allow the exploration of broader ideas (Baumgartner & Hensley, 2006). Current qualitative and quantitative studies may offer limitations in terms of their applicability to the New Zealand population, due to the changing technology, cultural differences and an expanding recipient pool with disparate pre-implant health experiences. Women are a minority in the ICD population and few qualitative studies have focused on their perspective of living with an ICD.

Gaining insight and a fuller understanding of women's' experiences of living with an implantable cardioverter defibrillator will assist health care providers identify potential issues and areas where increased or targeted support and education is needed, optimising patient care and experience with stronger and more responsive service provision. Obtaining a New Zealand perspective could strengthen local electrophysiology services.

Overview of the thesis

Chapter One – Introduction

The research purpose, aims and question were introduced in this chapter. It has also provided information about device technology, indications and clinical benefits, as well as prevalence both nationally and internationally, as back ground to previous research on ICDs and this study.

Chapter Two – Literature Review

This chapter outlines the literature that was used to scope this study, providing background on previously researched issues and experiences on life after receiving an ICD. This review was then used to plan this research and frame the interview questions.

Chapter Three – Methodology

Chapter Three outlines the research design and qualitative methodology, using semi-structured individual interviews, for this study, with discussion on the rationale and justification of these choices. Ethical and cultural considerations of this research will be revealed.

Chapter Four – Results

Chapter Four will present the qualitative data collected from participant interviews. Participant characteristics are outlined. The data is organised into four main themes, using the participant's voices to illustrate these. These themes are: the effect of antecedent events; physical realities and practicalities; positive value place on interpersonal relationships; and contemplating mortality. Numerous subthemes are also presented.

Chapter Five – Discussion

This chapter will provide a discussion on selected key issues identified from the data, focusing on those with relevance to nursing. The discussion will focus on issues around discharge, the impact of driving restrictions, the impact of being a mother on participant's experiences, depression and emotional adjustment, nursing and peer support for ICD recipients and end of life issues.

Chapter Six - Conclusion

The final chapter will summarise this study, acknowledging its limitations and strengths, along with presenting recommendations for nursing practice and further research

CHAPTER TWO

Literature Review

Literature review structure

This literature review will first outline its purpose and search strategy. It then will examine quantitative studies on specific facets or issues noted in the ICD population. These focus primarily on psychosocial function, specifically anxiety, depression and post-traumatic stress disorder. A discussion and review on research methodologies will follow, before qualitative literature on living with an ICD is briefly reviewed. The limitations of these studies regarding their application to the current New Zealand ICD population will be explored, refocusing the research question, directing the design of this study and the terminology used.

Original research question

What are patient's experiences of living with an implantable cardioverter defibrillator?

Purpose of the literature review

This literature review was used to broadly scope the study, providing background on the previously identified issues and experiences of living with an ICD. This was then used to plan the study design and frame the interview questions.

Literature review search strategy

The electronic databases PubMed, MEDLINE, CINAHL and Google Scholar were searched using the key words, Implantable Cardioverter Defibrillator. A variety of additional search words were used for specific areas of interest including, qualitative, experiences, gender, women, depression, anxiety, exercise, activity, life, living, death, palliative care, spouse, relationships and quality of life, although some of these areas were only identified after data analysis revealed them as relevant.

Quantitative studies

Psychosocial function

Personal adjustments to living with this implanted technology can be challenging, affecting quality of life and psychosocial function. Quantitative studies on ICD recipients have examined various aspects of life and coping post implant, using a variety of standardised testing tools and methods.

Anxiety and depression

Many studies have found a higher incidence of depression in ICD patients as compared to other cardiac patients and the general population (J. Burke, Hallas, Clark-Carter, White, & Connelly, 2003; Pedersen et al., 2011; Suzuki et al., 2010), although this may be associated with the underlying condition rather than as a direct result of the device. Dougherty (1995) found that depression and anxiety increased in patients who received ICD shocks. However, this is an older study, in which patients received 26 shocks on average per year, reflecting an earlier generation ICD. Newer ICD models have improved technology for rhythm recognition and treatment options are more extensive (van Welses et al., 2011). Despite this, Kamphuis, de Leeuw, Derksen, Hauer, and Winnubst (2003) and D. Carroll and Hamilton (2005) also found that shocks and anticipating shocks increase anxiety, even though the stress of anticipating a shock is less once the first shock has occurred. Cho et al. (2012) found baseline anxiety was higher in older patients and those who had previously been shocked. However, in younger patients and those with increasing non cardiac co-morbidities, anxiety had increased over time, although within this study 'baseline' and follow up times were quite varied.

Increased anxiety is an important consideration in the ICD population, as Kikkenborg Berg, Caspar Thygesen, Hastrup Svendsen, Vinggaard Christensen, and Zwisler (2014) found it to be the strongest psychosocial predictor of mortality. Both anxiety and anger are thought to precipitate ventricular arrhythmias, which can be potentially lethal (Dunbar et al., 1999; Lampert et al., 2002; Lampert et al., 2009). S. Thomas et al. (2009) found that 35% of all ICD recipients were anxious initially after their implant. Interestingly, this decreased in NYHF class III patients but not in class II patients who should be experiencing less physical symptoms in daily activities (National Heart Foundation of New Zealand, 2009). Kikkenborg Berg et al. (2014) also found that, overall, the primary prevention ICD population, which includes HF patients, had lower levels of perceived health and quality of life than the secondary prevention population. Both groups experienced moderate levels of uncertainty prior to implant, but secondary prevention patients had higher levels of uncertainty a month post implant, perhaps reflecting their prior experience with actual lethal arrhythmias and cardiac arrest (S. Carroll & Arthur, 2010). Flemme et al. (2005) found that, within a year, uncertainty had decreased in secondary prevention recipients and other quality of life measures had improved. However, van den Broek et al. (2014) found among Dutch patients that ICD indication or shock was not related to emotional or physical distress, which remained relatively stable after a small initial decline, but that inherent personality (type D) and anxiety sensitivity was a better predictor of distress.

S. Thomas et al. (2009) also noted that, in HF patients, depression decreased over time if no shock was received, especially in younger patients. However, this contrasts with a study by Friedmann et al. (2006) who found higher levels of depression in younger patients and those who had their ICD for longer. Mauro (2008), too, found younger adults to have more trouble adjusting but agreed with Flemme et al. (2001) that generally psychosocial adjustment improves over time. Different definitions and methodologies, as well as changing ICD technology and implant indications across this timeframe and for these populations, may account for these conflicting results.

Concerns about ICD devices are associated with higher rates of anxiety and depressive symptoms, irrespective of shocks (Pedersen, van Domburg, Theuns, Jordaens, & Erdman, 2005). Specifically, shock anxiety can cause pervasive psychosocial difficulties. Sears et al. (2007) found females and spouses of ICD patients had the highest levels of shock anxiety. As the majority of ICD patients were male, spouses would have been predominantly female suggesting shock anxiety, whether a patient or not, is highest among females. However, systematic reviews of research on gender disparities in quality of life and psychological distress have revealed that 80% of studies found no strong links to gender, as measured by patient reported outcomes, and therefore hesitated to suggest a gender difference due to insufficient evidence and confounding variables (Lauck et al., 2015). Biological gender differences in disease progression and incidence results in non-identical gender groupings, with women ICD recipients tending to be fewer but older, with worse heart function and more co-morbidities. Patient-reported outcomes may also be influenced by differences in how symptoms are experienced and reported and differences in gender role expectations, (Brouwers, Van Den Broek, Denollet, & Pedersen, 2011).

Post-Traumatic Stress Disorder (PTSD)

Experiencing a highly stressful event outside the range of normal human experience, like a cardiac arrest or ICD implant, can result in a psychological reaction called Post Traumatic Stress Disorder (PTSD). This is usually characterized by depression, anxiety, flashbacks, recurrent nightmares and avoidance of reminders of the event. There have been a few studies on PTSD in patients with ICDs. Habibović, van den Broek, Alings, Van der Voort, and Denollet (2012) found 7.6% of the 395 patients they tested, on implantation and at eighteen months post implant, met the criteria for a PTSD diagnosis. Device activation was not associated with PTSD, but baseline anxiety and type D personality were. Patients with PTSD clearly have increased levels of anxiety and depression but also an increased mortality risk (Ladwig et al., 2008).

PTSD rates range from 19% - 27% in out-of-hospital cardiac arrest (OHCA) survivors, but are consistently reported, as are anxiety (13%- 61%) and depression (14% - 45%). Variations across studies are most likely due to different methodologies, measures used and times since arrest (Wilder Schaaf et al., 2013). When comparing OHCA survivors with a matched group of acute coronary syndrome patients without arrest, Lim, Verfaellie, Schnyer, Lafleche, and Alexander (2014) found long term cognitive deficits and poorer quality of life in OHCA patients, but earlier studies showed no increase in clinically significant depression (Alexander, Lafleche, Schnyer, Lim, & Verfaellie, 2011). Middelkamp et al. (2007) and Andersson, Rosen, and Sunnerhagen (2015) also found reduced quality of life, daily functioning and cognitive function in patients with an hypoxic injury post arrest. About half of OHCA patients acquire a hypoxic brain injury (Pusswald, Fertl, Faltl, & Auff, 2000). However, Wilson, Staniforth, Till, das Nair, and Vesey (2014) found no difference in quality of life but an increase in self-reported anxiety and depression. Overall, most studies report that quality of life for survivors of cardiac arrest is reasonably good (Elliott, Rodgers, & Brett, 2011). As the majority of ICD recipients are secondary prevention, having survived a potentially lethal arrhythmia, measures of PTSD, anxiety, depression and quality of life may reflect the preceding health event rather than the device itself (J. Burke et al., 2003). Moreover, higher rates of patient anxiety and depression are found with most chronic diseases (DeJean, Giacomini, Vanstone, & Brundisini, 2013).

Review of study methodology

All of these reported studies are based on quantitative research, aiming to quantify or measure phenomena to test ideas about the nature of the phenomenon. They operate from a positivist paradigm, in which it is believed that an objective reality exists that can be studied and known. The biomedical model prominent in health care falls within the positivist paradigm where the world is viewed objectively to identify cause and effect to achieve control or predict outcomes. Quantitative research begins with a clearly defined theory and then aims to test it objectively following a pre-determined plan. This approach is reductionist in that it reduces experiences to those identified in advance, not recognising those that emerge during the process, thus limiting the questions and responses (Baumgartner & Hensley, 2006; Polit & Beck, 2014)

Alternatively, the experiences of living with an ICD can be asked from a naturalistic (or phenomenological) paradigm, a world view in which the meaning of events and feelings is important for individuals, informing their reality. So 'reality' becomes a subjective construct by individuals and the lived experience of the individual is important for understanding in order to help. This paradigm is holistic in that it considers individuals as a unified whole, consisting of

body, mind and spirit, to give a more accurate picture of the experiences within the context of those experiencing them (Pearson, Vaughan, & Fitzgerald, 2005; Polit & Beck, 2014). This paradigm lends itself well to qualitative research methods which emphasize meanings, experiences and descriptions as valid data, gathering narrative information through interaction with the researcher about patient experiences, meaning the findings are subjective and the researcher's interest is acknowledged. The research design can be flexible - driven by emerging information as insight is gathered and patterns are sought. This type of research is useful in helping to define and conceptualize little known issues and to provide an in-depth description about phenomena variations, dimensions, importance and meaning to individuals (Polit & Beck, 2014).

Qualitative studies

Various qualitative studies have been done internationally. The data gathered is subjective to the ICD recipients, but how it is grouped, interpreted and valued can also be influenced by the researcher, providing insights into real world experiences and issues (Polit & Beck, 2014). The nature of qualitative studies means that findings are not directly transferable between studies with individual researchers, gathering unique data and organising this into unique themes. However, common threads may be seen across qualitative studies (Polit & Beck, 2014), some of these themes will be explored next.

One of the larger qualitative studies of patients with ICDs reported by L. Burke (1996) involved 24 patients. It based its themes around technology, finding participants chose life with technology, integrated technology into life and lived life through technology. Dickerson (2002) identified technology as lifesaving yet "changing everything" for recipients post cardiac arrest. Locsin et al. (2010) also specifically referred to technology in the context of dependence. Several other studies also identified dependence as an issue, with patients being dependent on both the device and social support (Eckert & Jones, 2002; Kamphuis et al., 2004; Palacios-Ceña, Losa-Iglesias, et al., 2011).

Security is also a common theme, with ICD patients identifying feelings of safety because they have an ICD (Fridlund et al., 2000). This sense of security encompassed both patients and their family members (Eckert & Jones, 2002). Participants in other studies referred to this feeling of personal safety as living with "life insurance" or a "security blanket" (Conelius, 2014; Palacios-Ceña, Losa, Fernández-de-las-Peñas, & Salvadores-Fuentes, 2011). It is not always clear if these studies involved primary or secondary prevention populations, as

perceived personal risk in recipients who have experienced a prior cardiac arrest could impact on their feelings of dependence and security post ICD implant.

Patients' loss of control over both their health and when/if the ICD will activate is also a common theme. Some studies also recognised the themes of patients regaining control, adjusting to this change or developing strategies to help mitigate the loss of control, both adaptive and maladaptive (Dickerson, 2002; Eckert & Jones, 2002; Morken, Severinsson, & Karlsen, 2010). Several studies have expanded on this identifying a phase of adjustment and the ability to get on with living by seeing/believing in hope for the future (Dickerson, 2002; Fridlund et al., 2000; Locsin et al., 2010; Palacios-Ceña, Losa, et al., 2011; Tagney, James, & Albarran, 2003). Many studies have also found that having the ICD can restrict lifestyle and activities, especially around anxiety, and fallacies about device activation leading to avoidance behaviours. Some ICD recipients avoided activities they believed promoted arrhythmias, although some of these behaviours, like being in crowded place or using cell phones, are limiting and unsubstantiated. This behaviour is often prompted by fear of their ICD discharging and can be related to situations where this has occurred previously (Eckert & Jones, 2002; Flanagan, Carroll, & Hamilton, 2010; Kamphuis et al., 2004; Linder et al., 2013; McDonough, 2009).

Restrictions around activity post ICD implant was experienced as difficult for participants in several studies (Bolse, Hamilton, Flanagan, Carroll, & Fridlund, 2005). One study specifically acknowledged an initial deterioration in physical function, with women describing ongoing pain around the ICD site affecting sleep (Tagney et al., 2003). However, the three women interviewed by Conelius (2014) reported increased physical functioning. Lifestyle changes around driving restrictions were frustrating for participants in multiple studies, contributing to the feeling of lost independence (Eckert & Jones, 2002; McDonough, 2009; Palacios-Ceña, Losa, et al., 2011; Tagney et al., 2003). Tagney et al. (2003) found some participants had to adjust to temporary or persistent changes in their roles within their households and employment. However, participants appreciated and valued the feeling of 'getting back to normal life' (L. Burke, 1996; McDonough, 2009; Morken et al., 2010; Wojtecki, 2011). Partners of ICD recipients were also affected by these changes but adapted, with most reaching a point where they were able to feel in control again and normalise their lives (Albarran, Tagney, & James, 2004)

Changes in outlook can occur with ICD recipients re-thinking, examining and re-valuing the meaning of their relationships and lives, usually with gratitude and an increased awareness of being alive (Dickerson, 2002; Fridlund et al., 2000; Locsin et al., 2010; Palacios-Ceña, Losa, et

al., 2011; Saito, Taru, & Miyawaki, 2012). However, this response can also bring an acute awareness of mortality, with the ICDs presence being a reminder of death, which is troubling for some recipients (Conelius, 2014; Kamphuis et al., 2004; Locsin et al., 2010), although confronting personal mortality was not always perceived as threatening (Kamphuis et al., 2004). Some participants avoided making end of life plans and discussing death with family or physicians (Wojtecki, 2011).

Several studies referred to the importance and meaning that relationships with their family held post an ICD implant (L. Burke, 1996; Kamphuis et al., 2004; Palacios-Ceña, Losa-Iglesias, et al., 2011; Wojtecki, 2011). Supportive friends were also valued for preventing loneliness (Fridlund et al., 2000). While this support was appreciated it could become stifling and frustrating over time (Kamphuis et al., 2004). However, partners of ICD recipients expressed feeling they had to safeguard their partners initially and this feeling only receded slowly (Albarran et al., 2004; Palacios-Ceña, Losa-Iglesias, et al., 2011).

Some participants in these studies reported that professional support was useful, although many also noted information would have been more helpful if individually targeted (L. Burke, 1996; Flanagan et al., 2010; Morken et al., 2010; Tagney et al., 2003). Morken et al. (2010) found a lack of continuity and appropriate support post an ICD, with most recipients reporting insufficient information and support was provided. Linder et al. (2013) also found that effective communication with health professionals was limited by situational urgency and misunderstanding. Kamphuis et al. (2004) found physician contact to be limited and confined to physical check-ups, with the psychosocial effects and concerns about their ICD being rarely raised or addressed. Peer support groups were either desired or found useful by participants in some studies (Bolsé et al., 2005; Flanagan et al., 2010; Palacios-Ceña, Losa-Iglesias, et al., 2011)

Although common themes were noted in the literature, it may not be possible to generalise the findings accurately into the wider population group as the narrative nature of these qualitative studies means only a small number of individuals were studied. The qualitative literature reviewed involved between 3- 24 patients. As these qualitative methodologies involve interaction between the researcher and the participants, how well rapport is established and the researchers' communication/questioning skills influences the quality of information gathered. Some of these studies involved phone interviews, focus groups and others face-to-face interviews, potentially affecting interpersonal communication. The time and personal nature of the methodology may also impact on which participants agree to take part and the degree of co-operation from the subject in opening up about personal experiences could vary, also affecting the quality and nature of the data gathered (Coolican, 2009).

The interpretive nature of qualitative research means that it is open to influence from the researcher's personal values, knowledge and experiences (Coolican, 2009). Most studies cited in this review used a single interview to gather information for interpretation. However, studies by Palacios-Ceña, Losa, et al. (2011) and Flanagan et al. (2010) sought to validate their interpretations by re-reviewing recordings, transcripts and field notes from both parties as well as member checking with informants. To establish conformability Saito et al. (2012) discussed interpretations with an expert panel, including two nurse researchers, and member-checked meanings to obtain agreement, demonstrating a more robust research design.

Limitations of literature reviewed

Many of both the qualitative and quantitative studies reviewed may offer limitations in terms of their current applicability to the New Zealand population due to the changing technology, cultural differences and an expanding recipient pool with disparate pre implant health experiences.

Changing technology

Device technology has evolved since the first ICD was implanted in 1980. Early devices were large (8x 11.5 cm) and weighted 280g. Implantation required open heart surgery to place the epicardial leads and the device generator was situated in the abdomen. Early devices were capable of basic rhythm recognition and treatment algorithms and could not be reprogrammed. Occurrences of inappropriate therapy was more frequent. Current devices are smaller and leads are placed trans-venously negating the requirement for a thoracotomy, with the device generator now inserted subcutaneously by the pectoral muscle without the need for a general anaesthetic. Current devices are capable of greater rhythm discrimination and can deliver an escalating series of treatment before a shock is delivered. These treatment programs can be individualised and reprogrammed externally with the ICD insitu (van Welses et al., 2011). Certainly, ICD implantation has become less physically rigorous. However, many of the studies have taken place involving recipients of earlier generation devices, and may therefore reflect the physical and emotional responses to major surgery when patients receive a larger device that is more likely to shock.

Different cultural backgrounds

There is some evidence to support cultural differences in ICD patient's experiences, with Bolse et al. (2002) finding differences in the experiences of uncertainty and satisfaction between USA and Swedish samples before and after implantation. While the New Zealand health care model is based on the biomedical model like the rest of the Western world, how it is

organised and accessed varies across nations, which could also impact on patient experience. Universal health coverage is common amongst Organization for Economic Co-operation and Development (OECD) countries like New Zealand, however this has not been the case in the USA where many studies originated, meaning financial barriers to care for the uninsured and low to middle income people were notably higher for these populations than those in other OECD countries (K. Davis & Ballreich, 2014). Herman, Rissi, and Walsh (2011) found that having health insurance does not protect individuals from medical debt in Arizona, and medical debt and lack of insurance coverage both predict reduced access to care. Kalousova and Burgard (2013) and Kelley et al. (2013) also found medical debt to be a source of financial hardship and reason for individuals to forego medical care. This could have a significant impact on the patient population receiving ICDs in the USA, as well as their life stressors and experiences. The qualitative research on ICD recipients from the USA often refers to the average participant as male, college educated (more likely to be higher income) and often working. One study specified that their participants had medical insurance, and others reported patients referring to their ability purchase their device (L. Burke, 1996; Conelius, 2014; Flanagan et al., 2010; Locsin et al., 2010). Although a USA study by Bolse et al. (2005) strategically selected patients to achieve a broader patient spread, they did not look at financial access or stressors, issues that may not be as prominent elsewhere in the Western world.

Culture and environment has an over-arching influence on how we perceive and experience health and illness. Perceptions of New Zealand health care and its systems are influenced by and share similarities with other Western societies with a colonial history, like Australia and the USA, as well as our imperial origin, the United Kingdom. However, the New Zealand context is unique due to its geography and distinctive history, cultural mix and values (P. Davis & Dew, 1999). Therefore, findings in other Western societies about patient experiences may not accurately reflect those of patients in the New Zealand context. Only one quantitative study on the psychological implications of ICD implantation in a New Zealand population has been done. Newall, Lever, Prasad, Hornabrook, and Larsen (2007) found lower levels of anxiety and depression in ICD recipients in New Zealand than expected based on their review of international research. They suggested this may be due to the structure and follow up of this ICD service, providing reassuring staff consistency and continuity of care that may be lacking in some other centres. However, a relatively small sample population of 46 ICD recipients was tested which could skew the results, and while they excluded pre-existing depression, Newall et al. (2007) noted pre-existing depression was higher in the ICD population, perhaps reflecting the correlation between emotional dysfunction and arrhythmic events.

Benefit of further research

Gaining insight and a fuller understanding of patients' experiences of living with an implantable cardioverter defibrillator can assist health care providers identify potential issues and areas where increased or targeted support and education is needed, optimising patient care and experience with stronger and more responsive service provision. While some work has been done in addressing this question, much of it is quantitative with varying results around the effects and interactions between specific factors like gender, age, implant indication, device activation with shocks, depression, anxiety, uncertainty, PTSD and quality of life. However, with these studies it was unclear how influential the role of the ICD was and what impact preceding health events and chronic illness in general had on these results. Qualitative research has found some common themes but changing technology may be altering present recipients' experiences. Only one quantitative study involving 46 ICD recipients has been conducted in New Zealand, suggesting further local studies may be relevant to New Zealand electrophysiology services.

Refocused research question

After the scoping literature review, the research question was refined to focus this research on women's experiences. Female heart patients are underdiagnosed and undertreated. Gender based societal expectations within both medical and relational contexts influence women's experiences of heart disease and can inform optimal care (Galick, D'Arrigo-Patrick, & Knudson-Martin, 2015). Women's experiences are often lost in health research (Committee on Women's Health Research, 2010). Women also form a minority group in the ICD population and may have specific issues or concerns related to gender (Patel et al., 2016). Further literature was sought to address issues and themes that emerged from the data. These are included in the discussion.

Terminology choice

Much of the literature reviewed referred to their participants as 'patients' with ICDs, however, this study has chosen to refer to its participants as 'ICD recipients'. While patient refers to a person who is under medical care or treatment, it also is synonymous with long-suffering, and the personal quality of bearing misfortune calmly without complaint. Recipient simply means a person who has received, without these connotations (*The Chambers Dictionary*, 1997). This study aimed to capture the experiences of women living at home, in a non-medical environment, without the expectation that they would be either suffering or patient, so will refer to ICD recipients.

CHAPTER THREE

Methodology

Methodology

Epistemological theories are concerned with how we perceive and investigate the world, or the nature of knowledge and how it is obtained (Liamputtong, 2012). This research aimed to explore the broad experiences of women with ICDs, supporting the naturalistic paradigm by providing a worldview in which the meaning of events and feelings are important for individuals in forming their reality. Here reality is a subjective construct of the individuals and therefore a first person descriptive account of the individual's lived experience is important for gaining understanding (Jirojwong, Johnson, & Welch, 2014; Liamputtong, 2012). This paradigm is holistic in that it considers individuals as a unified whole, consisting of body, mind and spirit, to give a more accurate picture of the experiences within the context of those experiencing them. This paradigm lends itself well to qualitative research methods, which emphasize meanings, experiences and descriptions as valid data (Jirojwong et al., 2014).

Qualitative research studies focus on experiences from the first person or subjective point of view, examining the way we experience things and the meaning things have in our experience (Baumgartner & Hensley, 2006). Qualitative research allows the study of issues in-depth and for a wide exploration of experiences, opinions and behaviours. This is helpful to define and conceptualize little known issues and to provide an in-depth description about phenomena's variations, importance and meaning to individuals (Boswell & Cannon, 2014; Holloway & Wheeler, 2010). It is therefore appropriate to use a qualitative approach for this research. This will involve gathering first-hand descriptive information about participants' experiences through their interaction with the researcher. This can be a flexible research design, driven by emerging information as insights and patterns are sought. (Boswell & Cannon, 2014; Holloway & Wheeler, 2010; LoBiondo-Wood & Haber, 2014).

This method involves interaction with the researcher, so how well the researcher establishes rapport with the participants and the degree of communication and questioning skills they have affects the quality and nature of the data gathered, as does the participant's degree of co-operation in opening up about personal experiences. The comfort and co-operation of the participants may also be influenced by factors outside the researcher's control, like the physical environment the interviews occur in, whether they are alone or amongst others, time pressures and preparedness. Without co-operation, rapport and skill the data

gathered may be trivial and superficial (LoBiondo-Wood & Haber, 2014). However, both Arnold and Boggs (2016) and Boswell and Cannon (2014) agree that this intensive interaction can produce plentiful and meaningful information, with the ongoing interpersonal interaction allowing for issues to be highlighted and probed with follow up focused questions to clarify meaning. The quality and depth of the data obtained can directly relate to the interpersonal skills of the interviewer, and the interviewer's ability to project an engaging, supportive and encouraging manner. Active listening and acceptance is crucial. It is also important to establish trust and rapport with the participant as, if this is not accomplished, the data gathered can be skewed (Arnold & Boggs, 2016). Boswell (2014) also states that information can be skewed by differences in interview techniques and processes between multiple interviewers. To negate this issue of inter-rater reliability one interviewer was used for all participants in this research.

The data gathered is subjective to the individual but how it is grouped, interpreted and valued can also be affected by the researcher, influencing overall findings. If done well, however, qualitative research can provide insights into real world experiences and issues and provide a starting point for further targeted research or interventions.

A limitation of qualitative methodology is that the sample size is necessarily limited, usually by time and financial constraints, due to the labour intensive nature of qualitative studies. This also means that, due to the small sample size, findings may not be replicated by other researchers and other participants, therefore may not generalise accurately to the wider population (Polit & Beck, 2014). However, with qualitative research a larger sample size may not enhance understanding as it can lack depth and richness and the individual responses and meanings may become lost amongst the volume of data from many participants (Holloway & Wheeler, 2010).

This qualitative study obtained data via one-off, in-depth, semi-structured interviews with 14 adult women participants who related their personal experiences of having lived with an ICD implant for six months or longer.

Ethical approvals

Consent to conduct the research was obtained from the Eastern Institute of Technology Research Ethics and Approvals Committee, the institution studied with and the District Health Board Research Office in the district where the research was conducted. When originally submitted, both applications specified that participants in the research would be male and female. When the research later evolved to focus on women only, both these organisations

were informed. The documents showing ethics consent for the research are included in Appendices 5 to 7.

Ethical considerations

The main ethical considerations for this study were participant privacy, confidentiality and anonymity. The potential participant pool from within a New Zealand regional DHB was small, increasing the possible risk of individual participant identification. In this research confidentiality was raised with participants in the initial Information for Research Participants to Participate in Research and Consent Form (see Appendices 2 and 3), which states details that are potentially identifiable will be deleted or obscured. To maintain the confidentiality of information gathered and the anonymity of the participants, efforts have been made to remove identifiable features from data while maintaining some sense of context. Certainly all women are referred to by a pseudonym, with geographical and demographic data blurred. However, to maintain the context and autonomy of the narratives some background information is necessarily revealed. On informal discussion with participants during their interviews it was clear that they were aware that they formed a very small population and that their unique stories might be identifiable to those who know them or work with this population. It was with this knowledge that the women related the personal experiences recorded in this research.

The principle of anonymity does not necessarily equate with disguising every identifiable detail, although there is little guidance on how to achieve this in practice. Thesis supervisors provided guidance on anonymising data in this research project. Anonymity is a continuum, from very nearly identifiable to fully anonymous, with the researcher balancing maximising participants' identity protection with maintaining the value and integrity of the data. Practically concealing identities can be virtually impossible, as those close to the research setting and participants will potentially be able to recognise participants and places. Despite these difficulties, efforts towards anonymization of data should still occur as participants do not always have a clear understanding of how their words will be used (Saunders, Kitzinger, & Kitzinger, 2015).

All participants were coded by an identifying letter, and thereafter referenced by this letter in all transcripts and working analysis to help preserve anonymity. Letters were substituted with randomly selected short female names in the final draft of this thesis. Hard copy information on participants was kept securely in a locked box and digital computer files were password protected.

The researcher is employed as a registered nurse in the inpatient cardiology service of the DHB from which the participants were drawn and could therefore have had prior or have future contact with potential participants in this role. This was one reason why the selection criteria required participants' ICD placement to be more than six months old, thus providing some distance in time from when the researcher may have had professional contact with potential participants, as patients who had a secondary prevention ICD following a cardiac arrest and may have spent several weeks in an inpatient cardiology unit. This issue was also discussed with the Clinical Charge Nurse of cardiology and, with the patient care allocation system utilised in this workplace, it was arranged that patient loads would be allocated to avoid the researcher providing direct care of any participants who was readmitted, should this be necessary. These precautions, and the participants' rights, were specified on the Information for Research Participants form (Appendix 2), this communication to potential participants informed them that:

- You do not have to participate in this research if you do not wish to.
- If you are a patient or under the care of students or staff from EIT, you can withdraw from the research at any time and this will not affect your treatment or assessment in any way.

It is also noteworthy that part of the role of a cardiology nurse involves discussing how people are managing with their health and illness, so many areas covered in the research would be informally discussed with in-patients in this professional role. Holloway and Wheeler (2010) and Holloway and Freshwater (2007) agree that nurses often listen to illness narratives, as patients make sense of their situation and condition.

Research participants were encouraged to articulate and explore issues that were important to them. This can be therapeutic in assisting people to legitimise, integrate and absorb experiences. However, this exploration can also highlight or raise to the surface issues that are distressing, with the potential for psychological harm (Arnold & Boggs, 2016). According to Holloway and Freshwater (2007) the informal, intimate environment of individual interviews can also blur boundaries leading participants to reveal more than they intended or are comfortable with. In this instance, all participants had the option to withdraw from the research. It was also intended that if participants did become distressed without resolution during the course of the interview, they would be offered follow-up support services, with either the specialty clinical nurse in cardiac rhythm management or local mental health services, to help them regain their emotional equilibrium. No participant showed any overt distress during the interview process and the option of contacting the researcher later to discuss any issues or concerns was not utilised by any participants.

Research participants

The researcher aimed to interview between six to twelve adult women ICD recipients who had lived with an ICD for at least six months. This allowed the participants to have had time to experience life with an ICD beyond their hospital based experience. This sample size was considered sufficient for themes to emerge and is comparable with other qualitative studies in this field. For example, Conelius (2014) and Locsin et al. (2010) each sampled three participants whereas, at the other end of the range, Wojtecki (2011) interviewed 25 older adults with ICDs. Ultimately 14 interviews were included as the final two women to contact the researcher offered unique demographic backgrounds and the researcher wished to ensure their experiences were captured.

Inclusion Criteria: Participants in this research were adult women over the age of 18 years who had had an ICD implanted at least 6 months prior to the interview, who resided in New Zealand, were cognitively able to give informed consent and to converse fluently in English.

Recruitment

Once the appropriate ethical approvals for the research were gained, the researcher was able to access a client list from an electrophysiology clinic's database of clients with an ICD within a regional New Zealand district health board.

Using their clinical judgement, the electrophysiologists tasked with retrieving this list from the database chose to exclude eight names from the list before passing it to the researcher. This was to protect the patient, the clinical relationship or the researcher. Reasons for excluding patients on the list included factors such as a client's youth, significant active mental health issues or previous aggression in clinic settings. In total, 117 names were obtained, 35 of whom were women.

The information from the electrophysiology clinic included patient name, device type, model name and serial number. Patient names were located in the Electronic Clinical Application (ECA) hospital database and were checked to determine if they were still living, to confirm gender and to obtain mailing addresses. One woman was listed as deceased and no clear address was located for another. Another woman was excluded as she was a close relation of the researcher, leaving 32 potentially eligible women.

All 32 potentially eligible women were sent a formal invitation to participate in the research. This included, Information for Research Participants, an Informed Consent form and a more casual covering letter introducing the researcher (see Appendices 1 to 3). Subsequent

contact was initiated by the women who wished to participate, either by email or via a phone call to the researcher, to indicate interest in participation. If the inclusion criteria were met, an interview was scheduled at a mutually convenient time and location. Two women were excluded at this stage, one due to a language barrier and the other because her defibrillator implant was too recent. This left 14 women consenting to participate.

Information outlining the study was provided in the initial mail-out. Further information about what participating in the research entailed was also discussed when the participant made initial contact and before a meeting was scheduled. Formal written consent was obtained after clarifying the participant's understanding during the first meeting. An exception was the one participant who opted for a phone interview who gave voice recorded consent. All participants had the option of withdrawing the information they provided for the research up to two weeks after the interview process although none elected to do so.

Support people/third party presence

All participants were offered the option to have a support person of their choice present during the interview on the initial Information for Research Participants sheet (Appendix 2). The presence of a third party during an interview can affect the dynamic of the interview and the information gained. However, T. Smith (1997) felt most personal answers were hardly affected by the presence of a spouse or child and differences on gender role were spurious. Boeije (2004) found when interviewing about marital issues some participants' self-presentation varied when spouses were present and their opinions adjusted. Whereas, when also researching marital issues, Aquilino (1993) found that while subjective assessments could become more positive with a spouse present there was also a greater willingness to report sensitive information about the marriage. Quetulo-Navarra, van der Vaart, and Niehof (2015) acknowledged that with complex living situations it is difficult for some people to be interviewed alone and third party presence during an interview did not negatively affect data quality but improved it for most issues.

One participant opted to have a family member present who had provided an enormous amount of practical and emotional support to the participant throughout her ICD journey, including acting as a paid caregiver initially. This participant felt it was important to have her support during the interview to ensure she recalled events accurately and remembered what she wanted to say, as well as having their joint experience captured. They were initially interviewed together, both as active participants, but the ICD participant also

chose to continue talking without her support person for a further thirty minutes, which would allow for any variation or effect from the third party presence to be captured.

Two women had their husband present around the interview space for all or part of the interview. Both these women did not specifically request the presence of their husband but had arranged an interview situation where they were incidentally present and occupied in normal household activities like watching TV in a nearby space. This is consistent with Reuband (1992) who found that occasionally third party presence was sought overtly but often was unintended, with their presence condoned by the participant, perhaps reflecting an internal desire to obtain emotional and social support from others. He also found that direct intervention into the interview was rare from third parties and usually sporadic if it occurred at all. Both these women talked freely and frankly and would occasionally ask their husbands' opinion or seek support for their response to questions around relationships and roles.

One woman had arranged to be interviewed at her home while she continued to care for her children and grandchild. Toddlers were therefore present in the immediate environment and school aged children briefly interacting as they arrived home from school. While the children were not directly engaged in the interview process, the presence of the participant's family seemed to allow her to relax as she referenced them in the interview naturally. This woman also articulated that she was already open with her children about her health and experiences and did not appear inhibited by their presence around the home.

Data collection method

To obtain in-depth qualitative data about participants' experiences, individual, one-off, face-to-face interviews were conducted. Use of individual interviews gave participants privacy to discuss personal experiences in depth and with more confidentiality and freedom than can be achieved with some other data collection methods (Boswell & Cannon, 2014). An informal conversational interview technique was used, with conversational flow prompted as required with a semi-structured interview guide of open ended questions (see Appendix 8). This conversation gave women the opportunity to either focus on or begin in areas they felt important or where they were comfortable discussing, with the guide providing prompts to ensure all topic areas were covered. This allowed the interview to flow and questioning to evolve as data was gathered within the interviewing process (Coolican, 2009; Polit & Beck, 2014).

The questions guiding the interviews were developed after completing a review of the literature about experiences of living with an ICD and discussions with registered nurses, a

female relative living with an ICD and some of her family members. This was to gain a broad understanding of some of the expected or possible issues that may arise. Open-ended questions were used to ensure the opportunity was provided to capture these issues but without unwittingly influencing responses and shutting out novel or unconsidered issues (Arnold & Boggs, 2016). The initial questions were trialled in two pilot interviews; one with the female relation and the other with a registered nurse without an ICD. These pilot interviews allowed the researcher to check the phrasing, ambiguity and perceived meaning of the initial questions and to gauge the kind of responses they generated.

Suggestions and findings from the pilot interviews were incorporated into the final interview guidelines. These two practice interviews also allowed the researcher to gain confidence as an interviewer and to become more familiar with how to encourage flow in the conversation. Additional self-prompts to focus before the interview and on the process of introducing and concluding the interaction were also helpful in making the guide a useful working document. This piloting process allowed a more refined and relevant interview tool to be developed and for a more well prepared and confident interviewer (Coolican, 2009).

During the interviews, clarification was sought from participants through rephrasing and focusing questions as required. Summarising and reflecting on what participants revealed also helped them to clarify and articulate how they felt and how it related to other aspects of their lives. Several women sought feedback on their experiences or feelings during the interviews, asking if other participants had experienced similar things. Arnold and Boggs (2016) state that confirming responses can help to validate experiences and acknowledge their legitimacy. Reassurance that other participants had expressed similar issues legitimised the issues and helped some women to explore them more deeply.

The 14 interviews occurred between October and December, 2015. They took place at a time and location selected by the participant as a place where they felt comfortable and was quiet and private. Eleven women chose to be interviewed in their homes. According to Arnold and Boggs (2016), Holloway and Wheeler (2010) and LoBiondo-Wood and Haber (2014) this was a naturalistic setting in which it is easier to reveal deep-seated emotions and issues. Two women, however, chose the more neutral setting of a meeting room in a public library. One woman did not want a face-to-face interview and agreed to be interviewed over the phone. According to LoBiondo-Wood and Haber (2014) this is a more distant form of communication where participants' behaviour provides less guidance about how the language is being interpreted. However, valuable perspectives were still gained from this interview. Interviews usually lasted around an hour, ranging between 30 to 80 minutes in length.

Thirteen interviews were audio-recorded which allowed the interviewer to be more attentive and to listen more carefully without the pressure of needing to write notes, giving the capacity to check phrases and meaning later as suggested by LoBiondo-Wood and Haber (2014). An interview summary was written within a few hours of each interview to capture the researcher's immediate thoughts and reflections on the interview. A voice recorder was used with participant consent in 13 interviews. All audio-recorded interviews were fully transcribed by the researcher. One woman opted not to be voice recorded so more extensive notes were taken during her interview. Later she was offered and accepted the opportunity to review the written notes of her interview and confirmed that they represented her well.

Data Analysis

Qualitative data analysis results in an in-depth description of the findings, with language being both the raw material and the end product. There is no universal method for analysing qualitative data, but it often involves inductive analysis (Polit & Beck, 2014). Inductive analysis is a systemic data analysis approach where dominant ideas and patterns are identified from the raw data, as guided by the research question and aims, to form categories (D. Thomas, 2006). In this research a general inductive approach was used for analysing the interview transcripts. Basic demographic information was analysed using simple statistics to provide quantitative information about the participant sample.

Interviews were transcribed by the researcher to enhance familiarity with the contents and context of each participant's experience. Raw data from each of the transcribed interviews were broken down into smaller units of ideas or concepts. Holloway and Wheeler (2010) refer to this as extracting significant statements. Each unit or statement was then coded with the participant's unique letter, printed and cut up, allowing each statement to be individually examined and compared, looking for similarities and differences. This data was manually sorted with related ideas and concepts clustered, forming the categories or themes into piles of paper. These groups of overarching categories were fairly broad and abstract, each reflecting different dimensions of the individual experience. Following Polit and Beck (2014), these categories and themes could then be used to describe the participants' experiences of living with an ICD and became increasingly distinct as more data were analysed.

Trustworthiness

Trustworthiness and credibility can be an issue for qualitative research as the data gathering and interpretation is influenced by the skills and perceptions of the researcher. To increase trustworthiness clarification was sought during the interviews to ensure the

participant's meaning was understood. Direct quotes from the participants' interviews are used to bring deep descriptive authenticity to the themes and issues identified, leaving an audit trail that gives further credibility to the research (Boswell & Cannon, 2014; Jirojwong et al., 2014). At the time of the interview, participants were offered the opportunity to review their transcript and/or the themes/meanings discovered during analysis as being congruent with their experiences. This opportunity was also offered to the ICD recipient who piloted the initial questionnaire. According to Coolican (2009), participant member checking increases the research's trustworthiness and the probability that the information is relevant and transferable to others of the study population. However, only one participant requested to review the transcript of her interview, this being the woman whose interview was not audio-recorded. Her transcript was emailed to her for review and she voluntarily offered this feedback via return email. Her response was,

A beautiful transcript from your written notes. I'm happy with how it is going – I don't have any questions or amendments or need to clarify any part of what you have written. You are an excellent interviewer and are very clear and through with your writing.

Other participants requested only a summary of the findings on completion of the research.

Selected interview transcripts were read by the researcher's two supervisors who independently identified and coded themes for the analysis. These were cross-checked with the researcher's coding to support the interpretation and analysis of data. This provided multiple viewpoints and cross-checking on how the data reflected these, thus improving the trustworthiness of the interpretation (Coolican, 2009; Polit & Beck, 2014).

Considerations for Māori:

Māori involvement is seen as critical in New Zealand health research as Māori are disproportionately represented in negative health and well-being measures. How Māori may be involved and the potential benefits and impact on their health was considered and discussed with the Service Manager of the Māori Health Unit in the District Health Board where the research took place (Appendix 4). Consultation on this and research design methods can optimise the research's contribution to Māori health outcomes and ensure that the research process maintains or enhances mana Māori (Health Research Council of New Zealand, 2010).

Ethnicity was not considered a factor in participant selection for this research. However, it is of note that some of the precursor issues for ICD implantation, like HF and ischaemic heart disease (IHD), are disproportionately high in the Māori population. Among

Māori, HF generally occurs 10-15 years earlier than for non-Māori, with readmission and mortality rates approximately 8 times higher than non-Māori in the 45-64 age group (National Heart Foundation of New Zealand, 2009). In IHD, the mortality rate between 2000 and 2004 for Māori females aged 45-64 years was four times higher than non-Māori (Reid & Robson, 2007). Published data on ICD implantation and ethnicity was unavailable but it seems likely given the above factors that ICD is a treatment option offered to increasing numbers of Māori.

The qualitative research design works within the naturalistic paradigm, in which the individual's subjective reality and their personal experience is the focus. This holistic view is compatible with Māori models of health and wellness, such as Whare Tapa Wha, Te Wheke and Nga Pou Mana, which value a range of factors, including culture, as influential in health, as well as the open expression of emotion for well-being (Durie, 1999). In addition, support for the research was gained from the Service Manager of the DHB's Māori Health Service, following a discussion on cultural safety and suitability of the research question and method for Māori participants (Appendix 4).

Concerns were raised by the Māori Health Service that the participant recruitment process of 'cold calling' with a mailed invitation may be inappropriate for Māori and affect their uptake of the invitation to participate. In the experience of the Māori Health Service consultant, it was perceived that Māori would likely discard a letter and would respond more positively to personal contact. Because of the increased labour intensity of attempting to recruit via personal contact and the potentially greater pressure to participate if contacted by phone, the researcher elected to recruit participants via mailed invitations initially, planning more targeted invitations later if required. However, no targeted measures were undertaken as five of the women who accepted the mailed invitation to participate in the research identified as Māori.

One of the Māori women who did accept the invitation also expressed concern about whether Māori would be well represented in the project, stating that older Māori women were often very private and may be reluctant to talk with strangers about personal matters. The researcher therefore arranged an informal face-to-face meeting so the participant could get to know her and decide whether or not she was comfortable to proceed with the interview. On meeting she recognised the researcher from a previous professional relationship and chose to proceed straight to interview as a positive personal connection was already established.

The following chapter presents the data gathered from the interviews, structured around the themes that emerged from the analysis.

CHAPTER FOUR

Results

Introduction

This chapter presents the results from interviews with 14 New Zealand women who had been living with an internal defibrillator for more than six months. Demographic data is outlined first, with simple statistical calculations to give a brief quantitative picture of the women interviewed. Qualitative data gathered from the interviews has undergone an inductive thematic analysis, to identify dominant ideas and patterns, forming categories to reflect different dimensions of the individual experiences. These categories have then been used to present the data in a logical and manageable way. It is worth noting that, due to the complex nature of human experience, some categories are interconnected, impacting on and effecting each other. However, the broad categories that will be presented here are:

Participant characteristics

Effect of antecedent events

Physical device realities and practicalities

Positive value placed on interpersonal relationships

Contemplating mortality

These headings are used to group together key issues. Within each heading are subheadings focusing on specific aspects of the issue.

Participant characteristics

This section outlines demographic data on the 14 women who participated in the study. This data includes age, ethnicity, family structure, ICD type, indication and activation.

Participant age and time living with an ICD

The 14 women participants in this research ranged in age from 44 to 80 years at the time of the interviews, with the average age being 63 years. The average age at which they had received their first ICD was 59.7 years, with the youngest being at 37 years of age and the oldest being 74. The women had lived with their ICDs from between six months to nine years, with the average implant duration being 3.4 years at the time of their interview. Three women had required their device to be replaced with a new one either due to failing batteries or complications like infection or component failure.

Ethnicity

Five participants, representing 36% of the women interviewed, identified as Māori. This is more than the proportional representation of Māori in the national population. In the 2013 New Zealand census 15% of the population identified as Māori (Statistics New Zealand, 2015). One participant immigrated to New Zealand from the United Kingdom, becoming a New Zealand resident before receiving her ICD, and the remainder identified as New Zealand European.

Family structure

Of the 14 women interviewed, ten were living in households with another adult, nine with a spouse or partner and one with a parent. All participants had children. While the majority of these children were adults and living independently of the participant, both at the time of the participants' ICD insertion and the interview, four participants had dependent children living with them. The number of dependent children in a household living with the participants ranged from one to six children. These children were aged from a few weeks old to 16 years old at the time of the participant's ICD insertion and between two and 20 years old at the time of the interviews. All four women with dependent children had had a cardiac arrest preceding their ICD insertion. One woman cardiac arrested a few weeks after giving birth and another woman while she was pregnant. She went on to maintain the pregnancy and successfully had a live birth post her arrest and ICD. Two of the women interviewed were solo parenting dependent children.

Employment

Prior to receiving their ICDs seven women had been in paid employment, three were retired, two were below retirement age but not in paid employment and two were receiving sickness benefits. At the time of the interviews two women remained on a benefit and did part time work. One woman below retirement age was still not in paid employment. Five women were now retired, with two doing regular volunteer or committee work. Five were in regular paid employment and one was intermittently employed. Three of the working women had the same employer as they did prior to their ICD and two continued in the same role, with the other choosing to move to another position within the same organisation in the intervening time.

Driving status

Twelve of the women had held drivers' licences prior to receiving their ICD implant. Only one woman lived in a household without a licenced driver. In New Zealand the New

Zealand Transport Authority (NZTA) has control over the driver's licencing system. In order to ensure drivers are fit and competent to drive, there are a set of 'medical fitness to drive' rules which determine the medical conditions under which driving should cease. Current recommendations state that after a cardiac arrest and ICD insertion there is a six month stand-down period from driving, and a further six months each time an ICD fires. For a primary prevention ICD insertion the recommendations are at least two weeks of no driving, but most of these women report being told not to drive for six weeks (New Zealand Transport Agency, 2009).

As a result of these driving restrictions, seven households were left with no driver. For two households this restriction lasted for six weeks but for the other five households this meant six months with no driver, including three families with dependent children. Three women chose to drive against advice, and two others stated they obtained medical advice to drive earlier than originally advised. Only one of the women who drove early had dependent children, meaning that two of the women with dependent children spent at least six months running a household without direct access to a car.

Defibrillator indication

The events which immediately precipitated ICD implantation for these women involved a cardiac arrest requiring external defibrillation for ten of them, eight occurring within the community and two while in hospital. Of the four remaining women, one had an in-hospital cardiac arrest without receiving an ICD, but a further collapse at home a year later was attributed to a lethal arrhythmia that reverted with the force of her collapse.

We think I blacked out and hit the cupboard in the kitchen.... so no, it was a big one and they did say, the doctors, that it was only hitting the deck that bought my heart back.
(Rose)

Cardiac monitoring immediately post this event confirmed bursts of potentially lethal arrhythmias which then lead to her ICD implantation. Therefore, including her in the post cardiac arrest grouping of participants seemed appropriate, bringing their numbers to eleven, meaning 79% of the sample had a secondary prevention indication for ICD implantation. A woman with congenital heart disease received a CRT-D device to help manage her debilitating and recurrent non-lethal arrhythmias, with the defibrillation function included for primary prevention of cardiac arrest. The remaining two women also received primary prevention ICDs for structural heart disease severe enough to raise their risk of cardiac arrest. Both had a

cardiomyopathy and reduced ejection fraction, this meant that 21% of the participants received a primary prevention device.

Device type

The defibrillator function in a device monitors cardiac rhythm, only intervening if a potentially lethal arrhythmia is detected. All participants had the defibrillator function active in their devices. Eleven of these devices were ICDs aimed solely at intervening on lethal arrhythmias. In the remaining three the defibrillator function was attached to a CRT device, making it a CRT-D.

Cardiac re-synchronisation therapy (CRT) devices are used as continuous pacemakers to co-ordinate the chambers of the heart, improving the function of the heart as a pump, and are therefore useful for some structural heart disease. Three women interviewed had CRT-D devices, two were from the primary prevention category with structural heart problems but the other had had a cardiac arrest, initially receiving an ICD, but when the battery depleted in this device her heart function was re-evaluated and her ICD was replaced with a CRT-D device.

Device activation

While the CRT function on the CRT-D device is always active and intervening with the heart's rhythm, the function of the CRT-D and ICD for the management of lethal arrhythmias, should monitor and activate only when a lethal arrhythmia is detected. For the purpose of this research device activation will refer to defibrillation (or the 'D' part of both devices), where an electric shock is delivered to the heart in an attempt to revert the lethal rhythm. Acknowledging that, while both of these devices have techniques like anti-tachycardia pacing they can utilise briefly before attempting defibrillation, these techniques are painless and often go un-noticed when they occur. Also they trigger no legal restrictions on activities like driving, therefore the term device activation will refer to defibrillation or the firing of shocks (van Welsenes et al., 2011).

Five women, or 36% of the participants, reported device activation, with all of these women believing these shocks were appropriately delivered for lethal arrhythmias. With all devices of this type, there remains the possibility of inappropriate shock delivery without the desired trigger. One woman could not recall how often her ICD had fired as she experienced this as just dropping off and waking up. The other four women had received one, two, two and 15 shocks respectively.

Effect of antecedent events

The nature of the events leading up to an ICD insertion had a significant impact on the women's subsequent experiences. ICDs were recommended as secondary prevention for eleven women following medical emergencies and survival from a life threatening event. For six of these women this was also their first indication that they even had a cardiac problem let alone a severe one. These women all describe experiencing what started out as an 'ordinary day' before, suddenly, everything changed, when abruptly an unexpected massive upheaval occurred in their lives and offered actual proof of their mortality. For example, Pam and Tina each described this suddenness with their community cardiac arrests reporting,

My heart stopped. Just like that. I had no warning, I had no warning that it was going to happen, it was like somebody switched the light off and I just went blank. I had no inkling that it was happening... no pre warning whatsoever, it was lights out let's go. No pain, no nothing, just completely blank, it was a big shock. (Pam)

I just went bang, and fell on the ground, I have no idea what went on. I didn't care at all, I was quite comfortable. (Tina)

Lisa however, had an in-hospital cardiac arrest in the emergency department several weeks post-partum, after presenting to the hospital with her neighbour's urging due to a persistent and very severe headache. She also describes her immediate shock regarding her cardiac arrest,

How the hell did that happen? What is going on here? I came in with head pain and cardiac arrested! What I got was, this is how it is and it can happen anytime. (Lisa)

As well as their own shock, all the women in the secondary prevention group described noticing a sense of urgency and seriousness amongst their family, friends and hospital staff, around the fact that they had cardiac arrested. All these women remained waiting as in-patients on continuous external cardiac rhythm monitoring, while further testing was done and information gathered, before receiving a final recommendation of treatment with an ICD. This initial time in hospital varied from about a week to around two months. Rose described this period as,

The waiting! The waiting was horrible, sitting and waiting, day by day by day, lots of waiting. You know they wouldn't let me come home or let me go out, I had a holter

monitor on me the whole time. It was that wait, you know I started thinking, God is it today. (Rose)

Kate described feeling something similar after spending many weeks in hospital on this kind of cardiac monitor following a cardiac arrest while pregnant. She became desperate to go outside for fresh air and space away from the ward. While Kate appreciated that her nurses arranged for her to be “*allowed leave*” off the ward, to go outside the cardiac monitoring range with her partner, Kate found that she was nervous about being without the cardiac monitor and did not go far or stay away long. For her, the ICD became the device that allowed her to go home safely and move out of hospital.

Experiences of a sudden cardiac arrest precipitating a recommendation for an ICD contrasted strongly with the experiences of the three women who received primary prevention ICDs. These three women usually had device therapy introduced to them in an outpatient setting, or had it briefly mentioned while a hospital inpatient as being an option to discuss with their cardiologist later in an outpatient clinic. Therefore discussions around primary prevention ICDs occurred in the outpatient setting and medical recommendations given to the women could be considered over a longer period of time without the added urgency of a medical emergency like a cardiac arrest. Referrals for a device also took time, during which these women could continue to live their normal lives and could schedule and plan for when the device was to be inserted. Unlike the secondary prevention women, the women with primary preventions ICDs did not perceive being at home unmonitored without the device as unsafe or risky, possibly because, despite their awareness of the theoretical increased personal risk of cardiac arrest, it remained abstract. As Beth explained,

It was in the pipe line for about two years because I had a non-healing ulcer on one leg and of course they wouldn't do it while that was there. It didn't worry me, what will happen will happen. (Beth)

The women who received primary prevention ICDs seemed to feel more autonomous in their decision making, without the pressures and urgency experienced by the secondary prevention women. Unlike these women, who used words like ‘they wouldn’t let me’ and ‘allowed’, Beth, who received a primary prevention ICD, described freedom of choice,

You have a choice and I thought, some day it may be an advantage if at some stage you do have a cardiac arrest and you do want to live a bit longer and you are not ready to go yet. It was quite interesting to think, oh I don't have to but oh the consequences are.....

and knowing that the ejection fraction was not good and that I don't have a lot of symptoms when I have my heart attacks, that tipped me. (Beth)

The antecedent events leading up to the ICD insertion had a significant impact on the women's subsequent experiences with their ICD. Those who received secondary prevention ICDs after a cardiac arrest, felt the decision to accept treatment with an ICD was more medically driven and urgent, at a time when they felt physically and mentally vulnerable. Whereas primary prevention ICD recipients had more time and less medical urgency around their decisions to receive an ICD. This is essentially the difference between an acute life threatening event and a chronic impairment with life threatening potential.

Physical device realities and practicalities

This category is large, with several important subsections. Specifically,

- Procedure experience
- Experience of discharge home
- Changed physical condition post ICD/CRT-D
- Physical awareness of the device
- Physical activity
- Bedside monitors
- Device activations
- Complications with device
- Effect on other healthcare experiences
- Experiences around driving

Procedure experience

For all the women interviewed, the actual procedure of having the device inserted marked a major transition from life before an ICD to life with an ICD. While the primary prevention recipients were brought into hospital as outpatients to have the procedure and left promptly afterwards, resulting in a short planned stay, for the secondary prevention recipients it usually marked the end of an unexpected and often prolonged hospitalisation, causing some to respond to the transition with relief. Kate said,

Oh, they finally came along and said I was going to have an operation and I would be awake for the whole operation, but I just was so happy. (Kate)

Most of the women did not feel the need to comment on the actual insertion procedure, finding it fairly unremarkable, as Kate went on to explain,

The surgeon who did it was brilliant, he talked me through the whole thing, the operation, I could just see snippets here and there on reflections off mirrors and cabinets, but I couldn't see a lot. (Kate)

However, Kate was mid-way through her pregnancy when her ICD was inserted and, as the operation takes place in radiology, to minimise the foetus's exposure to x-rays her procedure was a little different than the others as,

They had about six of those covers over me! [lead aprons] So I could feel this really heavy weight on me, to cover the baby. (Kate)

Vera, who had had three cardiac devices placed, also described feeling confined during the procedure, commenting on how to improve the experience,

When they do the thing they strap your arms down and then cover you up with a sterile sheet up over your face, and some nurses make a lot of air around your face by pulling it up and others just go straight up and you feel bad enough with your arms strapped down without not having your face clear. So I feel that anyone teaching nurses should say 'and you make a little point and give them a little air around their nose'...I can understand why they need to have that over your face, but the different technique between the nurses... (Vera)

Vera also was able to compare her different experiences of the operator's techniques and pain relief. For her first device insertion she noted,

You only get a local and it was agony, and I've got a really high pain threshold and my toes were literally, you know how you say her toes curled up? My toes curled up and I said 'excuse me you are hurting me' and he never answered me, never said anything! (Vera)

Having a particularly painful experience of device insertion caused Vera to approach her device's replacement with increased trepidation. She was relieved to learn that the operator

she had had previously was no longer inserting devices and her second experience was much less distressing after she articulated her concerns,

I said this to [new doctor] when he did it and the putting it in was better... I didn't even know he had done it... I never felt it, it was amazing (Vera)

This more closely reflects the other women's experiences of the device placement as just being uncomfortable, with Kate describing,

I could just feel pushing, like pushing into your pocket or so. (Kate)

Whereas Fay briefly experienced pain during her procedure, vividly describing this pushing sensation as,

Everything was alright during the procedure until the end when he was putting the thing in when it was near the end and he was quite rough and he was pushing, and I said 'I can feel everything it is quite painful' and he said 'oh we'll finish in a minute', I thought it is like when you get a chicken and you want to put extra stuffing in it! (Fay)

The CRT-D implantation can be a little different from the ICD implantation as it can involve more than one session and an ablation. The CRT devices take over pacing for the heart, so in some cases the heart's intrinsic electrical triggers are removed by ablation during the procedure (Brignole et al., 2013). This ablation is an extra procedure that occurs alongside the device implantation. For Fay this meant two trips to the tertiary hospital, one for inserting the CRT-D and then later for an ablation and to activate the device, because, she said,

I had a total ablation on the AV node, so they had to make sure it was all wired up properly before they did that. (Fay)

The experience of ablation can be unusual, accompanied by a transient sensation of impending doom. Vera described her experience of having an ablation as part of her CRT-D transition from an ICD as,

My heart beat has stopped. They made me watch it on the screen, they said 'we are going to kill your heart beat', you could see it on the screen dribble away. It was the most amazing feeling and they said 'you will have a feeling of doom and then you will come right'... when it stopped I had an awful feeling of doom just coming over me. (Vera)

These women with CRT-D devices were therefore clearly aware from their experiences of its insertion that their lives were thereafter dependent on the device to promote a heartbeat.

Experience of discharge home

While the women were all keen to get out of hospital, particularly those who were inpatients for long periods of time after a cardiac arrest, how they transitioned home was difficult for many of them. As all their devices were inserted in one of two tertiary hospitals located out of their district, most women were discharged home from this tertiary hospital rather than from their local hospital. This meant that, while they usually went to the tertiary hospital in a hospital airplane with a nurse escort, they often had to use public or private transport to return home. Kate, for example, was driven home by her partner who was present during her hospitalisation. She described the trip home as keenly anticipated and very welcome but, *“horrible, I noticed all the bumps, the road seemed really rough.”* Gail was also driven home and appreciated this was the best of her options saying,

I was lucky my brother came and got me, you are not allowed to use this arm for six weeks, so you have got your luggage, your new device and your monitor... you know, you are not well enough to go on the bus on your own, and it was quite painful. (Gail)

However, at least five of the women interviewed were not able to access a support person to drive them home privately, and were therefore required to use public transport. For Jill this meant a five hour trip on a public bus after discharge from hospital, which she found to be mentally and emotionally difficult,

The next bit was a bit tough going, 'cause what they do is, they wheel you out to a taxi cab, you get a taxi to the bus station. To get put on a taxi stand and launched on your own is terrifying, absolutely terrifying! (Jill)

She went on to explain further just how physically difficult it was.

That was a nightmare, cause... I had been in hospital for a month after a cardiac arrest, to get put in a taxi to the bus station! I had hardly any clothes with me of course and I was so cold I actually had to get my dressing gown out and sit in my dressing gown! I was so cold, shaking, I wonder if it was shock as well, and sitting in the bus all the way, they had given me the thing that goes beside your bed and I had a box for that, I never had a case, I had two bags and this great big box, and they said, 'and don't lift anything!' (Jill)

The physical and mental stress that can be caused by travelling via public transport was recognised by Ana and her family. They successfully argued against her returning home on a bus, which was approximately a five hour journey to the district hospital and a further two hour journey home from there. Ana exclaimed,

They were going to put me on the bus! I couldn't even walk, and I had a two, three hour wait in [midway transit city]! You know, when you are not well, that is no way to travel...I said, 'I can't see how I am going to deal with it on my own!' (Ana)

Jill found she could not deal with the bus trip alone. She described how a stranger noticed how she was struggling to cope and intervened.

They had a stop for coffee...a lady on the bus said to me 'are you ok?' I said 'well I'm going to have to sit out here 'cause I can't get all my stuff and get a cup of coffee' and she said 'give it to me and I will help you', and I couldn't walk far, I had lost condition. (Jill)

Jill had suffered a post-procedure complication of a pneumothorax which meant she was unable to fly home as she had originally planned due the altitude and cabin pressures in an airplane worsening a pneumothorax. However, other women did utilize this method of transport. Fay flew home after her primary prevention CRT-D but also found it difficult and required assistance. She said,

So getting to the airport was a bit stressful. They said 'oh here are your discharge papers' and I thought, how am I going to get down stairs holding my bag? When you can't lift! Luckily one of the nurses was going off and he carried my bag downstairs and my daughter met me, and I went up to the airline and said 'look I have just had a pacemaker and I am going to need somebody to carry my bag'. (Fay)

For Rose, the experience of travelling home was isolating and frightening, a feeling which persisted even after she arrived home. As she explains it,

I was on my own, totally on my own. it is a lonely road, a lonely road, and I think the hardest thing is sitting at [tertiary city] airport when they put you on that plane to come home and you are just on your own. It is just a horrible feeling. You know, flying back, and you've just had surgery done, is pretty tough, pretty tough. (Rose)

For the women with secondary prevention devices, their discharge home is the first time they have been away from direct medical supervision, and often external cardiac rhythm monitoring, since their cardiac arrest. Jill described her discharge out of this medicalised environment as,

Daunting on the brain, and I do think that you do go into a wee bit of shock and you are terrified that it is going to happen again and there is nobody there. (Jill)

A cardiac device has a finite lifespan and may therefore require replacement, which for these women would mean returning to the tertiary hospital to have it done. How they were initially discharged home affected how they viewed the prospect of future travel and the procedures at these locations. Rose talked about how her device was reaching the end of its lifespan and would require replacement soon. Due to her experiences with her first implant, she was really not looking forward to this,

I think there are a lot of things that need to be looked at... You need to have a support person with you, 'cause it is a scary, scary time...It [ICD] will need to be changed, and that I am not looking forward to, and I know the funding is not always there, but it would be good if you could have someone there with you. (Rose)

Changed physical condition post ICD/CRT-D

Loosing condition

Jill described herself as having “lost a lot of condition in hospital” following her cardiac arrest and subsequent hospitalisation. Most of the women, like Jill, who had received a secondary prevention ICD, experienced a loss of physical condition and general weakness from inactivity during their hospitalisation. However, for Ana, the cardiac arrest triggered a cascade of physical consequences and complaints. For her,

Everything was breaking down, there was gout in my hands and my kidneys where playing up, everything was falling to pieces. (Ana)

This loss of condition meant that the women returned home weaker than when they left, which influenced their experiences post ICD implant as they therefore struggled to achieve the activity levels they were previously used to. Gail found this affected her ability to manage her usual household and childcare tasks, saying,

I mean I couldn't come back and do immediately what I did, because, as I was saying, I was considerably slowed down. (Gail)

For some women this weakness or loss of condition was a brief problem that could be worked through. Pam, for example, did a formal exercise tolerance test pre-discharge and was certain she “*could do more normally*”. Once she was back home she continued with her normal activities although she acknowledged increased levels of fatigue. She reported,

I was quite tired initially. I was feeling quite tired but then bounced back again when I got back into life and exercising. I got quite tired and had to go to bed early in the evening and slept really well, it improved my sleeping. (Pam)

For other women though, regaining their previous physical condition took longer and required personal determination and the encouragement and support of family members or carers. This was the case for Ana, who explained that goal setting with her support person/carer helped motivate her to gain physical condition,

There was a lot of setting your goals. Decide whether you wanted to get better or if you wanted to stay as you are...I think it is up to each individual, if you are quite happy to stay where you are or if you improve. (Ana)

However, all of the secondary prevention ICD recipients reported regaining the condition they had lost through their ICD insertion and related hospitalisation, to a level they were happy with, even if it took some time, as evidenced by Gail saying,

Now a year later I am so, so, pleased. Someone said it takes a year and think it probably does... I could barely walk from one end of the house to the other. (Gail)

Practical physical support was also necessary for Ana’s recovery. She particularly valued the support of a local family member who was present caring for her throughout her hospitalisation (“*day one to fifty one*”) and who then worked as her paid caregiver once she returned home. Unfortunately Ana’s home environment was not well set up initially for her return home in a deteriorated physical condition. Ana’s family member/carer was present for part of the interview, as Ana particularly wanted captured her carer’s perspective of their shared time transitioning Ana back to home. Her carer explained,

The easiest was when she was actually in hospital. Once she came home that was the hardest time. I was lifting her, she just couldn’t do anything, and trying to get things in process to assist her was difficult. So we had to create our own ways of doing things ‘cause some days, she could have a good day where she could get out there and take

her time and get out to the toilet or on to a bedpan, but nine times out of ten you were lifting her. (Ana's caregiver/support person)

Ana lived in a rural location which meant her access to some services and equipment was slower in coming than in more urban centres. Her carer would have preferred a better assessment of Ana's home situation prior to her discharge from hospital, but felt fortunate that she had experience working as a caregiver in this locality, explaining that she used her skills and established relationship with the area's occupational therapist (OT) to make the situation work. She said,

You can't just get it done that quick and you have to make do. Lucky I've been caregiving for years and years. I knew I will just get a board and will slide you across with that, and because I had that and because I already had a relationship with our OT, I would ring her direct and say 'are you coming through? I need so and so for this' and she was really good and I said 'and then when you come out, and when you bring that, can you assess what you think I might need extra?' And I think that worked out pretty good. (Ana's caregiver/support person)

While it took time, care and perseverance for Ana's physical condition to improve, she is now very grateful for the input and services that have enabled and assisted to her to regain her physical condition, so that she could say,

*I am standing upright and able to do things, be independent and do things for myself, which is something that at the beginning I never thought I would ever be able to do.
(Ana)*

Ana is also aware of some cognitive decline since her cardiac arrest, specifically around her memory. She and her carer reported that immediately post Ana's cardiac arrest her memory problem was quite severe, with Ana being unable to keep track of family or events in hospital. They felt that her memory had since improved significantly. In addition to keeping physically active Ana ensures that she keeps cognitively active also,

Weaving [flax] keeps my fingers going and keeps my mind going, and you know I love doing cross words and things like that, because of that, if you don't do anything like that your mind goes stagnant. Yeah, if you don't keep your brain active you could go downhill quickly and I have problems as it is, trying to remember things, and you have to keep those things going. (Ana)

Tina also experienced some residual memory problems following her cardiac arrest. She accepted this as a manageable consequence of her cardiac arrest and as something that she felt comfortable explaining to people. She said,

I had trouble with names. I would look at them and know I knew them but couldn't remember their name and I couldn't get the name, couldn't quite connect. I do have a lot of memory loss... especially if my kids interrupt me, if I am talking and I have to hold my tongue and then I can't remember what I was talking about. So I have to say stop interrupting me when I am on a roll... Sometimes people say - but I say 'I had a cardiac arrest and got zapped I don't know how many times, it does not help the brain' and they go 'Oh, ok'. (Tina)

Gail spoke of her memory issues as being temporary. After a period of post arrest amnesia, she now considered her memory and cognition to be fully functional,

There are two weeks where I have no recall, and I just say that is nature taking care of me. They told my family that I would be damaged, so I am still very pleased that I am not. (Gail)

Here Gail articulates her knowledge that cognitive impairment post a cardiac arrest can be severe and permanent. This knowledge underpinned these women's acceptance of their current deficits, as they did not feel too limited cognitively and were aware their mild memory problems could be much worse.

Gaining physical condition

Two women who received preventative CRT-D devices to stabilize their cardiac rhythm and improve their cardiac output talked about improvements in their physical condition following their device insertion. For Mere, a course of chemotherapy to help resolve her cancer gave her a “weakened heart that could not pump so well”, resulting in “lots of chest pain, didn't feel well, generally listless and tired, even just on showering which isn't very much activity”. While she feels her CRT-D had not entirely helped with her fatigue, she did acknowledge the difference between it working optimally and sub-optimally. When it was working sub-optimally earlier in the year, she was in atrial fibrillation and felt terribly unwell. She even visited her overseas children because she thought she was dying. Later with her heart in normal sinus rhythm and the rate increased from 50 to 60 beats per minute, she said, she “feels good”.

For Fay, the improvement in her physical capacity post her CRT-D was marked,

The quality of life that came, I mean, I'm 55 but I feel like a 45 year old now 'cause I can walk for miles like I used to, whereas before I would have to stop every second lamp post to sit on someone's fence to get my breath back... It is quite good now being able to go for a walk without gasping for air. It was quite bad there in the end. (Fay)

Fay's CRT-D changed her life, from experiencing frequent hospitalisations, palpitations and reduced physical capacity, to one that is more like others of her age group, causing her to comment,

Life is-, I feel like a normal person now. (Fay)

Physical awareness of the device

Initially painful

Post insertion pain around the ICD site was a common experience amongst the women interviewed. However, the scale of this discomfort varied between women with Fay describing it,

I have had a lot of hospital things but it was the most painful thing I have ever had in my life, the pacemaker, oh god, and I have got quite a high pain level. I couldn't do anything, it was just so sore. (Fay)

Whereas Pam found her ICD site to be mildly uncomfortable, with situational increases in discomfort which faded over time. Pam said,

It was just a little bit tender the first couple of weeks when I first came out of hospital, driving with the seatbelt on it that [hurt]!... I had a little pillow given to me... it was good, if I hadn't had that I would have been holding the seatbelt away all the time, and after a while I realised that I could do without it. (Pam)

Persisting physical sensations/pain around ICD

Once the pain from the initial operation had settled, several women were left with residual discomfort, either persistent or situational, around their ICD site. For Beth her ICD only caused positional discomfort, explaining,

Not actually uncomfortable normally, just if you lean on it, so you only really notice it in some positions. (Beth)

Enid also experienced positional discomfort around her ICD site which affected her sleeping position and therefore her quality of sleep. This was fairly common amongst the women interviewed. She explained,

Only when I sleep on that side, because I foetal sleep, [it's] just uncomfortable! So I roll on to the other side. I have never been one to sleep on my back but since I've had [the ICD] now I do because of the uncomfortable side of it. I don't sleep as well. (Enid)

Lisa described having fairly persistent discomfort, explaining,

I notice it a lot, sometimes it is actually quite uncomfortable. 'Cause it sits on my breast and it rubs a lot and I get quite a lot of knocks around there and it becomes quite uncomfortable. I find it annoying. (Lisa)

Like Lisa, Kate has dependent children. She found her ICD site and arm were often uncomfortable and aching, particularly around providing care for her baby.

When he knocks me, 'cause I was also breastfeeding, [how did you find that?...] well it was quite hard because, I mean, I know it is just here [gesturing]. But moving the boob around, kept it out of the way of it. (Kate)

However, she explained that her baby adjusted his behaviour to minimise her discomfort, saying,

As he knows it is mamee [sore] for mum, he settles on the right side and cuddles down, mainly leaves the left side alone. (Kate)

Kate felt that babies “usually like to settle and be soothed on the left side, over their mum’s heart beat” but as that was not comfortable for her, she thought her son picked up on that and settled on her right side. She was still constantly conscious of her ICD, as “it gets knocked all the time” now her baby is a toddler. The lifting involved with caring for young children also exacerbated Fay’s discomfort around her ICD, explaining that,

When they put this in they cut nerves and things, sometimes... sort of an ache, but not all of the time. I have got a granddaughter now and when I ... spend time with her, by the time I come back my chest is, you know [sore], from holding her. (Fay)

Tina spoke of feeling an unpleasant ‘crunch’ around her ICD when moving in some positions after she initially had trouble with a very mobile device. This was eventually repositioned and anchored more firmly in her chest as she explained,

They cut the muscle to put the thing at the back, I don't think it moves at all now, but you notice it...I can feel a crunch like it is moving on the bone, I can feel it if I put my hands up it feels like it is hitting there you know, it is a real blah feeling. (Tina)

However, changing devices can also improve the physical experience of them. For Lisa, her device required routine renewal and a replacement device was smaller and lighter, a feature that she appreciated, saying,

I get sore a lot in this area where the corners sit, but not as bad now as the device is smaller. With that bigger one it was really, like, banging into me. (Lisa)

Associated pain

The women who had had cardiac arrests required resuscitation prior to their ICD. For some of these women, especially those who had cardiac arrests in the community, this meant they received a lot of chest compressions until an external defibrillator was sourced and successfully revived them. These women described ongoing discomfort associated with the resuscitation during the initial phases of their ICD experience. While Pam described her ICD discomfort as “a little bit tender”, she describes her chest pain resulting from her CPR as “very painful”, and also more limiting initially than the insertion pain,

The first couple of weeks... it was very painful, more in the middle there, when you pushed right in you could feel like it was touching your backbone...in the middle of the chest you had that pressure. (Pam)

Tina also found the pain from her resuscitation to be a significant feature of her initial hospitalisation post her cardiac arrest. She spent several weeks recovering from this prior to receiving her ICD. Tina described this initial pain and its effects as,

They think they could have broken a couple of my ribs too, doing the CPR, but that didn't matter. I didn't care about that. When I woke up from the coma I think that was the worst of it, waking up and having it sore all down there and sore in my chest. It was just a real horrible pain. It was hard to sleep, hard to cough, 'cause if you coughed it was sore, but because you have got a cough you have to. They were putting me on codeine to suppress it. It didn't suppress it a lot but it helped a bit. (Tina)

Tina's resuscitation experience also caused her ongoing discomfort, with a sore throat that lasted a long time and a cough from her intubation. She reported,

When they put the tube down my throat it didn't go smoothly. He went crunching down, so, like, for nearly a year afterwards my throat was sore and right down to here [gestured to bottom of neck] and I had a really bad cough (Tina)

Jill also had a persistent cough, and an altered voice, for over a year after her cardiac arrest which she also attributes to her intubation. She explained this after a coughing spell during the interview.

[Coughing], that is the only problem I have got now, that is my throat. I think it is where they put the tube down. I keep getting a croaky voice and a cough, and phlegm gets caught, I can't shift it so I don't know if it will go or if it is there for good...but I am still alive, so... (Jill)

Consciousness of ICD presence

Physical consciousness

Distinct from physical pain from the ICD site, some of the women described a physical awareness or became increasingly conscious of their device. Several women found that, after their ICD implant, they needed to think more about and adjust things like their handbags and backpacks. When Mere went out on bush walks she found the straps of her backpack to be “a problem” so had changed her habits and “now carries lighter bags and less gear”. However, Fay explained that she had spent 50 years carrying her hand bag on her left side and even though it now hurts at times to have it over her ICD, she had not been able to adjust to carrying it over her right shoulder instead. She said,

I always carry my bag on there, but I do get tired and I carry it in front of me if I do ache. (Fay)

Kate was very aware of her ICD and particularly careful and protective of her device around her young children, explaining that she was,

Just really, really, conscious that it was there and of knocking myself. (Kate)

Whereas Lisa, who also had young children, denied being particularly aware of her ICD when interacting with and cuddling her children. She understood why some women might be physically aware of their ICD around children, but for her it was,

Just part of me so it doesn't phase them... it doesn't phase me too. Yeah it would have been a problem if I was breast feeding but I had already got him off, prior to going, so it wasn't a problem. (Lisa)

All the women denied altering their outer clothing to accommodate the ICD but some had altered their undergarments to increase their comfort. For example, Nora said,

[I] used to notice it when wearing a bra, [I'm] using a softer bra now as the strap was sitting right over it which was annoying me, so got the other type, now [it] doesn't bother [me]. (Nora)

Some women reported being hardly aware of their ICD, such as Mere who said,

Don't know it's there really, has melded in so well. (Mere)

And Pam who said,

I can't feel anything there, I know it is there, I can feel the shape. (Pam)

Nora noticed her ICD when she was naked.

I notice it in the bathroom, getting into the shower, I can see the outline quite easily, then I forget about it. (Nora)

Individual body shape and body fat seemed to make a difference to how prominent the women felt the ICD appeared, with Beth saying,

I'm ok as I'm not a skinny little wench but I'm not overly fat.... I mean you are conscious that it is there, conscious of it being there. (Beth)

Whereas Fay found that for her,

Mine is quite big and I am quite slim, you can feel the wires across here [upper shoulder] do you want to feel... (Fay)

Self-consciousness

Increased awareness of the ICD could alter the women's body image and manifest itself in self-consciousness. This concern appeared to be fleeting for most of the women and easily rationalised. Fay, for example, revealed,

I was a bit self-conscious from my husband for a while, but he - it doesn't worry him in the slightest, but in the beginning I thought you know, oh ok, but I soon got over that... it didn't last long, a few days and I thought I can't go on like this forever. (Fay)

Ana wondered how confident she would feel in her togs if she got back to her aqua-aerobics, thinking she might have felt a bit embarrassed about having an ICD. She then promptly compared herself to other women in her age group and changed her mind.

I was just wondering if this thing would stand out too much. So I think I would feel a little bit embarrassed, though when you come to think of it, talking to different ones that I know around town, the majority of them have got pacemakers. (Ana)

While the majority of the women acknowledged they noticed their altered physical appearance, they were not self-conscious or embarrassed by it. Gail said,

There is a tiny little bit of a scar, that bothered me before, but then you just think oh well it is not too bad. (Gail)

Jill also dismissed concerns about the appearance of her ICD, saying,

This sticks out a bit...It doesn't worry me, yeah you can see a lump but so what! (Jill)

Many women are comfortable with showing their ICD to others, even in public spaces. Pam explained that sometimes she triggers the security alarm at the local library when walking through. She deals with this by showing the librarians her scar and device outline,

I'm not worried about showing it to people at all... so I tell the ladies that I have got this thing in my chest, usually I just pull my top down and show them. (Pam)

Enid also comfortably refers to and shows her ICD at the educational institute where she works, often talking about it with interested school children there,

When I am showing them they are amazed that it is in there, it blends in so well. I show the kids and tell them that they can feel it in there, they go uugh!! (Enid)

Tina happily used her ICD and changed body image to tease her children who echoed the "uugh!" sentiments of Enid's school children. Tina explained,

I don't care if anyone sees the scar or sees it poking. I did freak my oldest out when I first got it. I was looking in the mirror and if you pulled your arm back you could actually see the box sitting up really well. So I said 'come here, do you want to see something really

freaky?’ and she said (keenly) ‘oh yeah what?’ and I pulled my arm like that and she said ‘oh Mum you creep!’ and she was, like, freaking out, and I said ‘you wanted to see something freaky so there it was!’ (Tina)

Normality - loss of abnormal physical sensation

Fay’s description of loss and change after her CRT-D and ablation after years of arrhythmias and external cardioversions highlights the range in the women’s experiences depends at least in part on the device type they had inserted and their indication for receiving it. She said,

Because my heart was always out or I could feel it racing even when it was normal, with the pacemaker it doesn’t seem to feel like the heart is beating anymore. So for the last 15 years my heart has been playing up and I could feel it all the time, it was like a friend had died. I felt funny, ‘cause it was always with me, before that I could always feel my heart beat pounding away - my friend. (Fay)

Vera also received a CRT-D for arrhythmias and reported the changed paced heart rate as,

It was just like having a normal heart... my adrenaline always stays the same, and that is what happens now it [heart rate] just stays the same, so it is very similar to my frame of mind. (Vera)

Both these women with CRT-D devices experienced altered physical sensations of their heart beat, because of the device’s consistent pacing, leading Fay to question,

Now is it working I wonder, is this what normal feels like? (Fay)

Physical activity

Coping with medically recommended restrictions post an ICD

The women referred to some of the behaviours and things they needed to avoid after receiving their ICDs. Restricting the movement, at least initially, of ones arms is medically advised after an ICD implant, to help it settle into place. However, some of the women had difficulty adhering strictly to this advice once they returned home and continued to manage their households. As Lisa explained,

I am very physical, so sitting down wasn’t an option for me. My sister was here but when she wasn’t looking I was up. I mean, I’m alright. I mean, they said don’t raise your elbow above so I would push it to there, no movement, nothing above the shoulders! ... I

got back into it quickly, at the six week recovery I was hanging my washing, luckily I am tall 'cause I was hanging my washing [awkward demonstration of how managed without raising arm]. (Lisa)

Beth agreed that performing household tasks, especially doing the laundry, was difficult initially and required extra care,

It was pretty difficult hanging the clothes on the line, you know I probably strung it up with the other arm, I can't remember how I managed, but I was pretty careful, I didn't want anything to go wrong. (Beth)

Kate interpreted her post ICD insertion instructions as requiring her to avoid electric appliances. However, she found this impractical when maintaining her household and caring for dependent child. She found,

Well, after my operation I came back, carrying on as normal and, 'cause for six weeks I wasn't allowed to lift my shoulder and things like that, I wasn't allowed to do washing... They say you are not allowed near electricals and things like that, but I was the only cook in my house, so I just did the cooking. (Kate)

Fay's problem was maintaining her personal grooming. She had long hair and explained,

I had to walk down the road, to a friend down the road so she could put my hair in a ponytail. (Fay)

All the participant's ICDs in this study were inserted on the left hand side of the women's chest. This placement was particularly limiting for the left-handed women, as Tina acknowledged,

Only thing that was really frustrating is, I am left-handed, and for four weeks you are not allowed to lift your arm. It is in the left side, so you are only allowed to go so far with your arm for four weeks which is really hard. (Tina)

Lisa also found this ICD placement frustrating as the left was also her dominant side, which she naturally utilizes the most,

For me it is because I am left handed. It is on my left side, so that is my strongest side. It was a big nuisance for me 'cause I couldn't do much and I felt hopeless, completely hopeless, it was hard to adapt, but I have got past that. (Lisa)

These comments highlight some of the short term adaptations the women had to make in their lives immediately after the ICD implant procedure and while it healed. For the left handed women the ICD around their dominant shoulder may effect longer term function as well. However, there are also longer term activities to avoid that can interfere with a device's programming or its physical position. The women were informed of these activity restrictions by healthcare staff, both verbally and in an ICD booklet. Nevertheless, Beth was grateful for her background as a health carer, as she found,

There was heaps of stuff in there that was irrelevant to me that is why I think it does make a difference if you understand medical terms, in the book. (Beth)

Who provided the information and the consistency of the message was important too. Kate said that, during her long hospitalisation, she got information from many people about many things, making it difficult to recall the context and value of the information. It is also possible that some of this information pertains not to the ICD but to medication or adjunct therapies around it which may be temporary.

[I] Wonder what is true and what is an old wife's tale, like avoid sun.... why? Do you melt? I have never set things off in electronic stores... Can't remember what advice or information was told by who, met lots of people. (Kate)

Some women independently sought out clarification or further information,

I did a little bit of research on the internet, it helped me, 'cause it would be different questions, so like you know, I wanted to know if I could have the electric blanket on, and they said, you know, turn it on, turn it off when you get into bed just as a precaution. (Jill)

Remembering and avoiding activities in the longer term was also a challenge for some women, like Lisa who said,

The hardest part for me was the first six months after, like remembering not to keep my cell phone near my chest, not jumping [starting] cars, no starting lawnmowers, and you know, things like that, that have got a magnetic pulse. And boom boxes which I am around a lot, with young kids. (Lisa)

However, most, like Jill, had integrated the restrictions they felt most relevant to them into their lives. Jill said she was aware of avoiding lawnmowers, microwaves and airport scanners, but otherwise she finds,

I just carry on with my normal life now, but I am very much aware of what you can do or you can't do. (Jill)

Activities of daily living

As well as the medically recommended restrictions advised after the ICD was inserted, the women were initially limited in their daily activities by the physical discomfort they felt. However, they tended to report this as transient, like Pam who said,

After the operation I was very tender and it took another couple of weeks before I could do activities, before I could raise my arm and lift things with a bit of weight... I don't think of it now... I am not having any problems doing my work at home. (Pam)

Tina felt that the purpose of her ICD was so that she could live and maintain her independence and so she was obliged to try, agreeing that the initially period was most difficult,

That is why I have got it, so I can keep doing things... I just carried on normally, well tried to carry on as normally as possible, but the first four weeks are the hardest... I am 'no, I can do it' and if I can't do it I won't. (Tina)

For some of the women the ICD, and the underlying heart problems that resulted in its requirement, lead to persistent issues with fatigue and stamina. Rose explained,

I have learned to live with it, I know what I can do and what I can't do. I pace myself. It is learning to pace yourself. Yeah, just sort of learning to know what you can and can't do, instead of going mad and trying to clean the house in one day, do it over three/four days, don't try and do everything at once. I just pace myself and make myself sit down and have a rest between... but I get it done. (Rose)

Very few women reported having had home help arranged by the hospital to provide assistance while their movements were limited and their physical condition reduced. Only Ana received extensive personal care and home help. Her carer noted,

So in a way she is lucky she had that support, 'cause imagine those that haven't! (Ana's caregiver/support person)

Enid also reported receiving funded assistance via the hospital when she first went home after her cardiac arrest and ICD. While she appreciated this help initially, she found eventually that she no longer needed it and the children of her extended family did some household tasks for pocket money. She explained,

I had home help when I got home, because they didn't want me to, you know, strain myself and that was good, but after a while I just said to the lady, cause I wanted to get up and get out again and didn't want to... I just used to look for things for her to do anyhow... there was nothing for the home help so we stopped that. (Enid)

Gail commented,

You don't get a lot of assistance, particularly when you are released from [tertiary hospital]. (Gail)

However, as time passed following their ICD insertion, most of the women interviewed expressed an attitude like Jill's, who said,

I'm fine as long as I don't do anything stupid. (Jill)

Exercise: activity beyond that of daily living

The physical ability and attitudes of the women to exercise varied, from being limited to being extremely active. Tina, for example, liked to keep active but her capacity was limited. She explained,

Well I exercise, well not exercise, exercise, 'cause I've [existing inflammatory condition], it is very hard 'cause I am limited in what I can do anyway, I don't do anything strenuous, I won't put myself out, I can't lift anything heavy. (Tina)

Many women found their own personal boundaries and comfort level towards exercise. Mere explained that while she can no longer run marathons she enjoys going on long walks, and chooses to only let herself get to a "good tired". She felt that it was,

Smart to listen to your body, because then you can do more overall. (Mere)

Pam also monitored her physical activity levels and body's response, avoiding more extreme exertion, saying that,

It doesn't enter my mind really, 'cause I know that what I am doing at the moment is fine. I am not making my heart race. It [ICD] might send alarm signals if I was doing some really physical exercise...going hard out, but I am not prepared to put myself hell for mail. (Pam)

In contrast Lisa was comfortable extending herself,

I push those boundaries, ok I will listen for a little while but nah I'm going to do it! I think what made me push the boundaries was that [ICD technician] told me that they could actually tell if it [ICD] even moved a fraction. So I thought well I'm going to push my boundaries and they haven't said anything, so I'm going to keep doing it. (Lisa)

Fear and misunderstanding can also limit activity. Jill mis-interpreted the reasoning behind the legal requirement of six months off driving after a cardiac arrest. This restriction is intended to prevent harm to the public, if control of the car is lost during a potential cardiac arrhythmia. Jill saw this restriction as a reason to limit her physical activity during this time, even though an event while walking will not cause the same problems. Her rationale was,

Wee walks, I thought I don't want to go too far! I thought if I can't drive what happens if I walk? I thought the same thing. I thought if you worry that it goes off, what happens if I walk and it goes off? (Jill)

However, after her cardiac arrest and ICD, Kate was “straight into walking and on her bike once home”, especially once she was no longer pregnant. She explained that she “bikes everywhere, to get around everywhere and stay fit and well”, including biking her children to and from school, but,

I am just really conscious of what I do and of knocking myself, and I get some shortness of breath, but I bike around a lot to just sort of keep that fitness. (Kate)

As Kate explained, she felt that physical contact might harm the device and so was wary of some other physical activities. Unfortunately this increased sense of physical vulnerability also affected her professional life as an educator as she then explained,

With kids it feels a little dangerous, I have taught a few hard kids, throwing books and things... would want to avoid athletics at school also... as could harm the device. (Kate)

Unlike Kate, who was nervous of and avoided activity that could involve physical contact with her ICD, Lisa was unique in this study in that she had continued playing contact sports after her cardiac arrest and ICD. Sport was a big part of Lisa's life and identity. She had been playing at regional representative level since a teenager and “it is a big part of my family too”. Continuing to play was very important to Lisa after her ICD. Her attitude was, “I wasn't giving up! I was playing [contact sport] whether you like it or not!” Prior to recommencing playing, she did however, have a discussion with her cardiologist about her desire to continue playing and check that this was not being overly irresponsible.

I asked my specialist... I said 'look I play [contact sport] and I love it', and he said 'look if you feel comfortable we have no problem with you playing, as long as you protect your site', so I play. (Lisa)

Lisa explained that, as she had been playing sport for a long time, she felt confident that her ability and skill would protect her physically, stating,

I can take a hit and I can give one too! (Lisa)

Lisa followed the cardiologist's advice though and protected her ICD site each time she played contact sports. The act of "padding up" reminded her each time of her ICD. She had evolved her own way of padding the site so that the padding remained in place during the game, covers the area and allows free movement of her arms,

So I have got to pad it all up before I play. I can't wear normal shoulder pads, they do nothing for me. I actually use a t-shirt, I wad it up and I make sure it is strapped on from here to here [from your armpit across to your sternum], Yeah and that is my shoulder pad, so I never wore shoulder pads anyway 'cause they were uncomfortable in there and they move so the safest thing for me was to strap my own. (Lisa)

Receiving medical clearance or permission was necessary when Lisa re-joined her sports team, as there was resistance from her club. She was frustrated by,

How discriminating how people were because I had an ICD... they think oh my god!... They didn't want me to play and they were trying everything in their power to stand me down from playing. 'Cause they were concerned about me and about them being liable, but it was about me, 'cause a lot of them were family. The only discrimination I have found is when I wanted to play sport they were like oh no! (Lisa)

Tackling this perceived discrimination took some perseverance from Lisa, who identified her mother as her main objector.

My mother actually went around and said I wasn't allowed to play! So she was my biggest obstacle...She was worried, and was, like, 'what doctor would let you play!' And I was like, 'Mum, I have asked the doctor and he said ok'. (Lisa)

Medical advice and approval, however, can be ambiguous for women and can be a barrier to some activities. Ana was quite physically run down after her cardiac arrest and ICD. As her health improved she considered going back to aqua-aerobics, which she had previously

enjoyed. She checked with both her local general practitioner (GP) and her visiting cardiologist about whether this would be suitable and received conflicting advice. She regretfully choose to adhere to the local advice and not return to this physical activity, as she explained,

What I couldn't understand is, I was going to aqua classes and I stopped going. After a while I thought I had better go see my GP, I thought I had better just ask her if I could go back. She said 'no, too much pressure on the heart' and I said 'no, I am not going to go there and swim lengths, just tread water and you know do a little bit of exercise'! So I thought oh, I had better go and see my cardiologist, so when he came down here I said 'could I go?' and he said 'yeah I could go to the pool and just take it easy'. I went back to my GP and I asked again and they said 'definitely not', and I said 'oh, who do you listen to, the specialist or the GP?' So I haven't been back, and I miss my aqua, you know it was good. (Ana)

Travel

Fay's CRT-D improved her cardiac symptoms and stopped her frequent hospitalisations which meant she could travel away from her local hospital. She explained her increased opportunities and freedom to travel as,

Well I haven't been able to travel before 'cause my heart was always going out... well my husband is [nationality] so we want to get there, but since we have had the grandchild it is more fun going down there. (Fay)

Vera initially found her device offered increased opportunities for travel also and she has taken several international holidays since it was inserted, saying,

When I first got it I thought it was the most wonderful thing in the world and I was proud of it and we went to [overseas] for a holiday and things like that, and really started living again. (Vera)

Most women did not seem to feel inhibited about undertaking international travel with their ICD, with several having travelled overseas since their device implant and others planning journeys. Women often travelled to visit family overseas, particularly to Australia. Some women followed medical advice before travelling internationally, like Mere, who explained that she travelled with her cardiologist's awareness and "wouldn't have gone if her said not to". However, on her last trip, Vera travelled against her cardiologist's advice, reporting,

He said I wasn't allowed to go [overseas] but I went anyway so when I got back I sent him a card and said you wouldn't guess what happened! I had a cardiac arrest, so I won't go again, unless I win a lot of money and then I am off again, and he has put that card in my records. (Vera)

The women who travelled were all aware that their external monitor was portable. Some women chose to take it with them when travelling, even within New Zealand, whereas others felt that was unnecessary if only away for a few days. Some of the women took their monitor overseas. Mere decided against it as it was “only for three weeks”, whereas Lisa took her monitor overseas for three weeks but then did not use it, saying,

I forgot all about it... so the whole time I had it over there it stayed in my suitcase. (Lisa)

Kate had only travelled within New Zealand since her ICD implant. She took her bedside monitor with her on these trips, but found it a little frustrating, saying,

When travelling around New Zealand I have to take it [bedside monitor] away with me... then when we are staying with other people I need to explain what it is. (Kate)

Vera took her external monitor overseas, which had been useful in providing her with information about an event.

When I took it with me, I had a cardiac arrest, I sent them an email the next day or something to [her tertiary monitoring hospital] and I got an email back saying yes on ... such and such a day you went into cardiac arrest, so it even worked all that way which I thought was amazing. (Vera)

This information was reassuring for her as it allowed her to make choices about follow up care that would have been difficult in the overseas rural area she was in. As she explained,

There was a little country hospital, when I had that cardiac arrest out on the farm. I thought oh maybe I should get it checked out seeing I am away from home. I rang and asked if I could speak to the cardiology ward and the receptionist went 'why, what do you want to ring them for?' I told her that 'my ICD, the device in my heart, had fired' and she said 'you don't need cardiology you need mental health unit! Just one moment', but I hung up before she could put me through. (Vera)

Given this response, Vera chose to rely on the information from her remotely monitored ICD and her conversation via email with the monitoring technician and seek no further medical assessment while overseas.

Travelling internationally carried an increased financial risk to the women if they required healthcare while away. Some women have investigated travel insurance to mitigate this risk. Most commonly insurance was found to be either unavailable or limited. Vera reported,

*I knew I would never get insurance for my heart in fact my insurance was only \$400 as they only did my teeth, my bones and my luggage, they wouldn't do any soft tissue.
(Vera)*

Beth said,

I won't be-able to get insurance. They wouldn't insure you if you have had this that and the other. So if the worst happens, it might get quite expensive coming home. (Beth)

The women managed well with the practicalities of travelling abroad. When travelling with an ICD airport scanning devices are to be avoided, requiring a personal search at the security screening. To facilitate this, ICD recipients are provided with a card when they get their implant, specifying they have a device and what type. Lisa found this card useful when she travelled, explaining,

*It was an experience telling them I can't go through... They looked at me like you look too young! I think they thought I was having them on, and I said I've got the cards if you want to see them. It was an experience being patted down and the dogs put on me!
Then it is an advantage too 'cause you get to skip the queue. (Lisa)*

While Vera worried about the airport security scanner it had never been an issue. Her husband, however, did not enjoy the extra time it took, Vera explained,

That was my biggest worry and travelling being forced to go through one of those things, them saying you can't go on the plane unless you go through this thing. But they never did, they just patted me down... My husband hated it because when I was going through customs on trips... they would say while you we are patting you down, we'll look through your husband's luggage, and he hated that... but they really patted you down, looked on the soles of my feet in case I had currency glued there, and through my hair. (Vera)

Nora described travel with an ICD as requiring extra planning,

[It's] more of a nuisance. If I'm going away I have to make sure I take tablets. I've got two boys [overseas], now when I go away I've got to take medication, make sure I get through customs with it. Got to let them know at the scanner, got to let them know I have a card... So not quite as simple as before... I had nothing to worry about a year ago, and something now that you've got to be aware of and take into consideration. Not a worry just a consideration. (Nora)

Bedside monitors

All of the women interviewed had an external accessory device that can wirelessly download information from their ICD/CRT-D about what arrhythmias it has detected and what, if any, interventions the device has used. This accessory is becoming increasingly common with current ICDs and downloads at regular pre-set times during the night so is usually kept beside the bed. The women commonly referred to this as their bedside monitor. Once information is downloaded it is transmitted, either via a phone link or satellite, to a monitoring hub. The location of this hub depends on the device brand and the hospital responsible for its service. This can be the women's local hospital electrophysiologist or, as some women reported, to an overseas company linked via a tertiary hospital in New Zealand (Lampert, 2013). The women had differing attitudes towards this remote monitoring via a bedside monitor. For Rose it provided a sense of security, that things are stable and alright. During a recent house move she lost her bedside monitor's cables and felt quite stressed until she acquired replacements from her local electrophysiologists. She explained,

I've got to have it, you know, it is like a safety net. (Rose)

Lisa used her bedside monitor as reassurance that her increased activity levels were not causing trouble with her heart rhythm, as detected on the remote monitoring, so therefore she felt safe to continue and increase her activity levels even further, saying,

Well I'm going to push my boundaries and they haven't said anything, so I'm going to keep doing what I am doing... and that is what that [bedside monitor] is for, to worry about me, not me. (Lisa)

Lisa also referred to letting the monitor worry about picking up issues with her heart rather than having to worry about them herself. Jill expressed a similar feeling about her regular palpitations saying,

I can feel a missed thing or something like that but it must be alright, 'cause they get print-outs from the machine. (Jill)

As Jill alluded to, at the other end of the transmission from the bedside monitor there is someone remotely monitoring the download which means that, if the women are concerned, they can contact the device's provider for reassurance or advice. Jill explains this further, referring to her heart palpitations,

I don't ring her every time I have one 'cause I think, oh for God's sake, it is just one of those things... but no I wouldn't ring [electrophysiologist monitoring device] unless it was really, no I would then, I would ring her straight away. (Jill)

Being able to access the ICD information remotely allows the monitor provider to identify and assess problems with the ICD recipient earlier than if the device is only downloaded during the recipient's clinic checks every three to six months. Enid's first ICD did not have a bedside monitor and when it required replacement her electrophysiologists specifically chose one with a bedside monitor so she could be monitored more closely. Enid said,

Apparently I had a couple of malfunctions and didn't realise, so that's why they gave me the monitor, because they said so we know, and they gave me that monitor and said that I had a couple of things, but I never felt them. (Enid)

Tina and her electrophysiologist utilized Tina's ICD remote monitoring function to identify the need for her to urgently see a cardiologist. Tina explained,

My monitor was going off, it was beeping... so I rang them up and said 'my monitor won't shut up, it won't stop beeping' and they said 'do you know why?' and I said 'I haven't got a clue'. She rung back that afternoon and she said that 'you need to come in' and I said 'why?' and she said 'cause the monitor is beeping 'cause on [date and time] your defibrillator was going to engage'. (Tina)

This contact with an electrophysiologist is not available instantly, however, but only within weekday working hours, and requires the machine to have done an overnight routine or a specially requested download. This delay was not reassuring for some women, as Tina went on to explain,

Just a bit worried about the monitor at home, because the night that it nearly kicked in was a Sunday, but it wasn't till a Wednesday till it [bedside monitor] noticed, I thought that was a bit strange! (Tina)

Ana was also disconcerted to discover that the remote monitor was not continuously reviewed. She explained,

I just sort of clench up, so that's it, but it is only for a couple of seconds, so you sit there until somebody rings me and tells me that something has gone on... Say if it happens on a Friday afternoon, sometimes I don't hear from [electrophysiologist monitoring device] maybe until about Monday or Tuesday! You know... that the machine has actually gone off! And [the electrophysiologist monitoring the device] says no I was off [work] on the Friday so until I go back to work on the Monday I don't know, so I say, so the whole weekend there is no one fully manning the place!?! And she says well no, there is no one manning it in the weekend. (Ana)

Ana's carer agreed that the delay in contact was disconcerting and worrying at times, particularly as they lived in a small rural centre without easy access to the electrophysiology clinic or a cardiologist. She said,

We would sit there and we could see it happening, we could see her having a turn, and we would think oh no, and go down and check the monitor and no nothing there, and that would take a while... but you wouldn't have that contact direct from [tertiary hospital] saying look we think Ana has had a turn, so that made us think, Jesus is this monitor working? (Ana's caregiver/support person)

Like Mere, other women were aware that their electrophysiologist only reviewed their monitor downloads weekly. The women interviewed also had regular clinic appointments to check their devices, usually three or six monthly. Mere describes the downloading and check-ups as a "reminder that all is not well", but also views it "like taking a car to get a service, needs WOF, rego, etc, which are just things to do, part of owning a car," meaning she accepts the check-ups and bedside monitor as part of the experience of having an ICD.

Having a bedside monitor was frustrating for some women. For Tina the frustration came from trying to get the technology to work properly. After experiencing an unusual feeling around her ICD she rang her electrophysiologist for advice and was asked to do a manual download using her bedside monitor. She explained

Well, my monitor wouldn't work and was just being a pain, so in the end, later that afternoon I had to go out to the hospital and be put on the monitor out there... she tested it and she said keep trying to test it at home and it was being such a pain, it just wouldn't work. I don't even know if it worked the last time... I rang [phone provider]

who my phone is through and they put the phone on a different frequency and I think that helped... (Tina)

Kate found it “annoying” having to have a fixed sleeping location to be near the bedside monitor. With two young children she often moved between bedrooms at night to help them settle, which meant moving the monitor between rooms. Beth also found it to be inconvenient and annoying to have the monitor near her at night as it cluttered the bedside table. She explained,

Well, because my husband is deaf, it is one thing. I have little drawers each side of the bed, and I have a little lamp on my side and a monitor, but I can't fit a telephone on as well and he can't hear the phone when he has his hearing aid out he can't hear at all, and that is a nuisance, but you know you don't really want a big table by your bed. (Beth)

Nora described initially feeling her monitor's presence in her bedroom as intrusive, saying,

As far as I know I'm connected to [local hospital]. Truth is it's a bit of an intrusion actually, but I don't think about it now, it's just there. (Nora)

Jill and Fay both commented on the monitor lighting up at night when it was downloading. Jill said,

Sometimes it is funny that machine in your bedroom. The first few nights I thought, ohh My God what is that! (Jill)

And Fay,

Then my little box in the bedroom! I like a dark room, it was like a light show, there is so many blinking lights on it that I thought, oh I am not going to be able to sleep and got up and got some duct tape and taped over all the lights. When it is downloading it is like a laser show, but it is funny I am used to it now. (Fay)

All women in this study had bedside monitors with their ICD. Their feelings towards their monitors ranged from dependent, viewing it as a source of security and reassurance, to doubt over its function and concerns over a delay in information being transmitted and processed. Technical issues with the monitor and transmission could be frustrating. Several women found the physical presence of the machine to be initially disruptive in the bedroom but generally they accepted the bedside monitor as part of having an ICD.

Device activation: shocking

An ICD's function is to monitor the intrinsic cardiac rhythm and intervene if potentially lethal arrhythmias are detected. This intervention could include anti-tachycardia pacing (ATP) for ventricular tachycardia, or a defibrillating shock for either ventricular tachycardia (VT) or ventricular fibrillation (VF). However, while the women were at increased risk of these arrhythmias there is no certainty or time frame in which they may occur, so some women may never have their defibrillator actually activate or shock them.

The women interviewed varied in how they viewed prospective shocks. Several had not received one. Beth, who had a primary prevention ICD, was surprised that her cardiologist thought she would want to experience this, saying,

[Cardiologist] said 'I suppose you want it to go off', I said 'NO why would I?' I thought what a funny question, who would want to be shocked. I suppose he thought to reassure me that it was working, but you know, that what will be will be. (Beth)

Tina had a secondary prevention ICD and had never received a shock from it. She dreaded the consequences of receiving a shock as well as the physical feeling. She described having experienced her device becoming ready to shock, only to have the shock aborted just prior to its delivery when her rhythm spontaneously reverted to normal. She revealed,

It didn't need to fire but I was that close to losing, not losing my licence but not being allowed to drive for six months... don't want it to ever go off 'cause I heard that it hurts horrendous, I mean, I have never been kicked by a horse so I don't want to be kicked by one now. I don't want to lose the driving either, that is my biggest thing. (Tina)

Fay also had a primary prevention defibrillator. However, she had never driven a car so did not fear the consequences of being unable to and is more interested in the physical experience of receiving a shock. She said,

I wouldn't mind seeing what it was like, because the pamphlets I've got say some people say that it is like being kicked in the chest by a horse and some people say they don't even notice it. (Fay)

Of the 14 women interviewed, five had received appropriate defibrillating shocks. Their individual experiences and physical awareness of the shock varied. Enid received her first shock shortly after her ICD was implanted while still in hospital. Later she also received a shock at

home with her husband present. She felt that having had a shock in the medical environment of the hospital helped her to identify and cope with her second shock, explaining,

So when I had this one here, I knew because I had one at the hospital, what it was, and I thought it's doing its job. 'Cause my husband got a bit of a fright you know. He saw it thump, saw me jump and I just felt a little bit woozy and he said, are you alright? And I said 'yeah I'll just have a little rest' and he said 'nah I'll take you to the doctors'. (Enid)

However, previous experiences of an ICD shock were not necessary for women to realise what had happened to them. Mere received her only shock when in the community teaching a group of people how to harvest flax. She explained that she,

... remained awake, dropped my tools and fell to the ground. Knew it was my defib, but felt ok in myself, so rested and was alright again. So didn't get it checked out for a couple of days. (Mere)

Gail had two shocks within 24 hours a few months after her ICD was placed. The first woke her from sleep and her second occurred in bed at the hospital later that evening. While having her shocks was stressful, they took away some of the uncertainty about how it would feel, saying,

At one level having a shock was useful, to know what it is like... I decided at least I have had that practical [shock], so at least I do know. (Gail)

The women seemed to accept that delivering a shock is the function of the device. Enid explained her experience of having a shock while walking across her lounge.

It just went boom, it thumped me, I didn't feel any different, you know what I mean... it just, out of the blue, it functioned, but that is what it is meant to do. (Enid)

Gail found receiving two shocks within 24 hours difficult to cope with after having had a heart attack and then a community cardiac arrest and ICD implanted all within a few months. However, after reviewing pictures of her abnormal heart rhythm prior to the two shocks with her electrophysiologist, she recognised the shocks as being “absolutely” worthwhile, explaining,

I sailed through the cardiac arrest, it really didn't worry me, but what did worry me was my device went off twice in 24 hours, the two times were both appropriate... Everything else I had coped with really well, but that one [shock], especially... 'cause it gives you a hell of a thump, but, as I said, having seen both times the funny line - I have seen them and I know. (Gail)

The physical experience of a defibrillating shock varied for the women. As out-lined above, Mere, Enid, and Gail all remained conscious and were engaging in routine daily activities like sleeping, gardening and walking in their lounge, prior to their shocks. These three women all described being thumped by their device shock. However, the other two women who received shocks had always lost consciousness prior to their defibrillator firing. This can reflect different lethal arrhythmias, with VF always resulting in a rapid loss of consciousness as no blood is circulated to the brain. With VT, levels of consciousness can vary depending on its rate and the underlying cardiac capacity and therefore output (McCance, Huether, Brashers, & Rote, 2010). Ana reported that she had never been aware of her arrhythmias and shocks, so she has no idea how many shocks she has had. She describes a typical shock,

I can sit here and sometimes I will have a bit of a doze and [husband] will just tap me and say 'are you alright?' and I will say 'why?', and he notices the change when he thinks there is something wrong. I just sort of clench up, so that's it, but... it is over in a couple of seconds and he says you had a bit of a turn... [Electrophysiologist] says did you have a bit of a turn or something, yeah and I says, well according to my husband he said I did, and she said, you had no idea? And I said, no I never do. I said I just get to the stage that I clench for a couple of seconds and it is all over, so if anything was to happen it did happen pretty quick. Well, she said, well it did. (Ana)

Vera had three cardiac arrests in hospital prior to her first ICD and has had 15 appropriate shocks from her devices since then. Like Ana, she has not felt the device fire as she too loses consciousness, explaining,

Although I have had 15 shocks, I haven't felt any of them. Right out boom! No pulse, no breathing for 42 seconds, and then the thing kicks in. I don't feel anything at all. (Vera)

However unlike Ana, Vera is often briefly aware that she is about to lose consciousness prior to her shocks. She describes this sensation vividly,

I've got time to say two words. I can feel the blood draining from my head and it goes down to my eyes and I go blind and just before I go blind I have time to say 'I'm going'... Like it is just draining down and I've got the 2 inches to quickly say something... Then if [husband] is with me or if I'm with someone who knows what I'm doing, it means they have time to stop me from really going with a bang... Well the last one I had I can't remember any warning at all and others when I come around I think, oh shit that is what it was! (Vera)

Losing consciousness is about losing control of oneself. This feeling of loss of control is one that Vera has had often and particularly dislikes. She explained,

Even in hospital I didn't like not being in control. Like one time I came around and the last thing I remember was hearing somebody calling out 'help me help' and I said to the nurse as I came around 'what happened to that poor woman who was calling out?' and she said 'I think she is feeling quite good now', and it was me! Yes I don't like passing out. (Vera)

Vera explained that she did not mind passing out as much if her husband was present, as he knew what to do and could control the situation for her while she is unconscious. This is important to Vera as she was reliant on a CRT-D device and feared that attempts at manual resuscitation if she was unconscious could cause harm and prevent the device from working. She continued,

I don't mind if my husband is there, because I'm not allowed to have CPR, 'cause if I have CPR it could dislodge the cables and I am totally reliant on the cables. So when I collapse he has to go 'no, no just leave her alone'. (Vera)

How best to manage resuscitation with an ICD was a concern shared by a few of the women interviewed. Lisa attended a first aid course and debated what should and would happen with her tutor. She said,

I got told that you don't need to be defibrillated because I have got it [ICD]... I just said I don't need that and he was like, well you know not everybody knows that, and I though hang on if you do defibrillate me I think I have got more chance of being dead and all that if it is shocking me and you are shocking me you will be killing me wouldn't you? So the first aider and I were like, I would give my device a chance before I go and do it, but it is like he said... anyone could be there and their reaction would be to defibrillate me. (Lisa)

Jill also had similar discussions at her work place, were they have already performed CPR on her, about what they should do if it occurs again or her ICD fires. She said,

The key, I think, is they need to give you something to give to people about what to do if it goes off, right, and because they know you have it, they think well so what do I do? (Jill)

As well as her concern about what treatment she will be given when she is unconscious, Vera found that repeated shocks made her feel much less confident. Vera's situation was unique in this study, as she had received many more shocks than all the others, therefore her situation and reaction to multiple shocks will be explored in more detail. Decreased confidence is a big change for her as she had previously enjoyed a public career involving performing in front of large groups of people prior to receiving her ICD shocks. However, she explained, since "the first one", this has changed.

Fifteen times in seven or eight years, that is not a huge number but each one [shock] is a real bash to my confidence. (Vera)

Vera reports feeling embarrassed and fearful of falling in public spaces where others will see her lose control. Her collapses and shocks make her feel very conspicuous and inelegant, the centre of a drama she cannot control. She said,

I am terrified that I will go into cardiac arrest in front of thousands of people... it is being a very conceited person who doesn't like collapsing... I mean it makes a big bang when I hit the floor! When I was an actress we used to just slide to the ground in a swoon... It is nothing like I learnt at drama school! We used to swoon... we don't go bang like a tree! (Vera)

Ana also referred to the potential problem of collapsing in public. She attended many meetings and community groups and had collapsed at these meetings when her ICD shocked her. She talked about one collapse and acknowledged that the situation could have been worse if she had been more visible and standing, saying,

I was at a meeting, just sitting at the table, you know you don't get any sign or anything! I just was sitting there talking to someone, and all I did, I sort of leant to one side for a couple of seconds, until someone tapped me on the shoulder and said 'are you alright?' and I came out of it fairly quickly and I said 'no I'm alright, what happened?' And they said 'I think you had a bit of a turn', and by that time they had already rung the ambulance... but at least I hadn't been standing up in front of a crowd. (Ana)

The effect Vera's collapses have on other people has increasingly concerned her, particularly as the number of shocks she experienced had increased. She now tended to avoid public spaces, not just to avoid potentially embarrassing situations for herself but to prevent other's distress, explaining,

I just don't like now being in public, more for the sake of the public than for me... [Husband] does all the shopping now, I haven't been inside a shop for 5 years. Once again that is the fear of dropping in the queue or something. (Vera)

Vera gave an example of her defibrillator activating, in a public situation that was distressing for others. She explained that she was in the waiting room at her doctor's surgery, just reading the *National Geographic*, and then,

It shocked. I flew back and hit my head back on the wall and I came around and I said 'ohhh, I have the most dreadful headache' and one of the patients waiting to see the doctor said 'no bloody wonder you have got a headache, you have nearly broken the bloody wall!'... I just sat there saying 'I'm sorry, I'm sorry I'm so sorry'. I was so sorry I'd frightened the other patients, one man ran off... (Vera)

Over time, and after increasing ICD shocks, this feeling of loss of control and the fear of frightening others meant that Vera reduced the activities she undertook and the locations that she felt comfortable being in. Vera had been very active in public speaking but had given up this aspect of her life. She recalls,

I really miss it now. I haven't been able to do any [public speaking] since I collapsed there, 'cause I don't want to do it [collapse] in front of a group of people... I do think that when you are [old] you aren't doing as much anyway, but it really made sure that I didn't. (Vera)

Embarrassment and concern about where she was, who was there and what she has done, are things Vera thinks of each time after a collapse and device shock. She describes collapsing in the hospital in front of a cardiologist. This was the only time she lost control of her bladder, but it has become a consideration each time for her now,

There was these lovely shiny brogues this far from my face and I thought, oh no whose feet are those, someone who has seen me fall down...pee all over the floor... I was more embarrassed in the hospital about wetting the floor than anything else. (Vera)

The potential loss of bladder control and concerns that during her collapse she will injure herself impose further limits on some of Vera's activities outside her home, as she explains,

I love visitors coming in here [home] but if we get invited out, we don't often accept them, to go to somebody's place. I probably got it in my head that I would bleed on somebody's carpet. (Vera)

In summary, five of the 14 women had experienced appropriate and successful shocks for arrhythmias from their ICD and none had experienced inappropriate shocks. Some women remained conscious during their arrhythmias and shock while others did not. The women appeared to cope well with individual shocks but found it more difficult to maintain a healthy psychosocial attitude with shocks in close succession and over cumulative shocks. ICD shocks and loss of consciousness can make women feel vulnerable and limit their interaction with the wider community.

Complications with an ICD device

A few women described complications or issues with their ICD devices. These complications caused increased medical surveillance, hospitalisation and surgical intervention, resulting in extra inconvenience, risk and worry for the women. Unfortunately, as well as experiencing the most ICD shocks, Vera was also one of the women who experienced complications over the course of her three cardiac devices.

One of these potential complications is infection. Infection is a risk with any surgical procedure. A device-related infection caused Vera to become critically unwell. Vera began her cardiac device experience with a permanent pacemaker (PPM), after an in-hospital cardiac arrest, *“although at the time I thought that was a bit ridiculous because I needed something to stop the heart”*. She described seeking help as she felt increasingly unwell afterwards.

I felt really ill, I had the most ghastly scar like awful barbed wire thing and I just felt sicker and sicker. I went to my lovely young doctor [‘John’]... I went to him and I lay my head on his desk like this and said ‘John’ I’m dying, I really am and I am going to die right here on your desk’. ‘Oh that’s interesting’ he says. He rang [cardiologist] and said ‘you are going to have to do something she really is not well’. (Vera)

Vera’s GP arranged admission to hospital with the cardiologist. She subsequently cardiac arrested in hospital, leading to her being flown through *“a terrible storm”* to a tertiary hospital where her original PPM was removed revealing the extensive scarring and pockets of infection which had triggered this chain of events. Her PPM was replaced with her first ICD. Vera recalled,

They whipped out the pacemaker, which was the problem and put in the ICD and gave me a lovely clean scar... He kept saying to the nurse ‘come and have a look at this would you!’ and it was all the damage the other bad doctor had done and pockets of infection... Apparently I was really really ill... I didn’t think I was that ill, just a cardiac arrest. (Vera)

After her experience with an infected device, Vera is particularly aware of the risks of infection. Another complication she had experienced was having a device that moves. Vera described how her third, device a CRT-D, is no longer “tucked in nice and firmly” in her chest, but interventions to anchor it are considered undesirable by her cardiologist because of her “terrible risk of infection”. Vera describes the moment she detected that her device started to move vividly, with,

One morning I woke up and could feel [movement] on my chest and I thought it must be a rat, so I had a look and it was the ICD sticking up like that, up under the skin!... it did a flip and went back over here, and I thought oh I don't like this very much. So I went to my doctor and I said, my ICD has come away from its moorings and it is just migrating backwards and forwards whenever it feels like it. And he palpated it and he nearly went white as this went ZZHong zipped across my chest. (Vera)

She explained,

It [ICD] decided to go walkabout. It only goes this far but that is still too far, [15cm right across to the middle of your chest], then it came here stood up on its edge, it has only stood up on its edge 2 or 3 times, comes right up on its edge and does a really big slow turn, like a baby turning and then slithers back, a really weird feeling. (Vera)

Tina also recalled waking one morning frightened,

I woke up because I felt something go like that across my chest and I thought oh what is that? And the defibrillator had actually turned. It wasn't very nice, poked out on its end I was, like, oh my god what am I going to do, how am I going to fix this!... It kept moving and I kept telling them that and they said 'no, no, it is fine', until the wires twisted. (Tina)

Both Tina and Vera wondered why their devices suddenly began moving. Both had cardiologists who wondered if they had “fiddled with it”. Vera said,

[My cardiologist] tells me that these thin people play with theirs. They palpate it and they fiddle with it, but there is too much fat to get through before I can fiddle with anything. (Vera)

Tina also refuted this explanation,

I said to him how do the wires twist and they said 'do you fiddle with it?' and I said 'what do you mean?' 'Do you sit there and twist it?' and I said 'oh uuuuh, no it is bad enough when it sat up on its side, let alone touching it!' (Tina)

Twisted wires can occur from a mobile device and are problematic as wire or lead damage can affect whether the ICD will appropriately or inappropriately monitor and deliver treatment for the heart rhythm. Tina had experienced this further complication. She explained,

I was fine till last year, 'cause I have a check every six months at the hospital, they put the little doodacki over it and said 'one of your wires is reading funny'. I said 'yuh and... how does this matter to me?' So they x-rayed me and called the cardiologist, and I knew that as soon as they walked in, I knew I didn't want to see him, and what had actually happened is that one of my wires had twisted. (Tina)

The damage to Tina's ICD wires was considered to pose a significant risk to having the device malfunction and required her wires be removed and replaced. However, this procedure is technically difficult and can require transition to emergency open heart surgery, as Tina understood,

There is only two guys in NZ who replace the wires so they had to get him down... and needed to have a cardiothoracic surgeon in the operating theatre... They said when they pull the wire out it can rip the vein and that is when they would have to crack me open and do everything, but it went really well, you know, I didn't mind, it was just disruptive. (Tina)

For Tina, this complication meant a further post procedure recovery time with reduced mobility to her arm and increased post procedure pain,

I think getting the wire changed hurt more than the defibrillator. Then again, that is because they cut the muscle to put the thing at the back... and they stitched it to my collar bone. I don't think it moves at all now, but you notice it. (Tina)

Rectifying this device complication also caused disruption to her household and childcare arrangements. Tina is a solo parent and this occurred just prior to the school holidays. Tina spent a week waiting in the local hospital before she argued to be able to spend a further week at home while waiting for the necessary team of doctors and resources to be brought together at the tertiary hospital where she was transferred to.

[My cardiologist] imprisoned me in hospital! I wasn't impressed with that!... He wouldn't even let me go home to get a change of clothes! He said 'oh anything could happen', and I said 'nothing has happened in the last six months' and he just looked at me, so I had to go to hospital to wait... just frustrating... disruptive, I didn't like it at all! (Tina)

For Lisa, a faulty rather than a twisted lead caused her device problems. Like Tina she also found herself suddenly in hospital having surgery, which also required her to leave her family with several young children. Her problems were identified through abnormal reading via her remote monitoring, as she explained,

So they actually rung me and said 'oh have you been having problems with your heart?' I said 'no why?' 'Because we are getting readings of 240 [beats per minute]'. I said 'no I have been absolutely fine'. So they waited about a week and said to me 'oh we think you might have a faulty line', that is the lead going in, so they shot me up that day [to tertiary hospital]... it was a faulty lead! So they left that in there and threaded another one in. It was a higher risk pulling it out than it was putting it in, so now I have got two leads in there. (Lisa)

Kate's medical team was concerned that her ICD leads might be faulty or displaced, but at the time of the interview she was still waiting for a final diagnosis and plan while further information was being gathered. She reported,

Just a month or so ago... they found a displacement on one of my wires, I haven't heard anything back yet, so they were just waiting for x-rays or stuff...so I'm still waiting to hear back on that... they are concerned because all my readings are different at the moment. (Kate)

Tina experienced a further complication when the manufacturer's settings changed (rather than her device readings changing), causing her another fright. She was at her daughter's school when her device started alarming at her, a startling feeling that caused her to say,

'Oh my defibrillator just vibrated', and they were like what? and I said 'it is ok I'm not going to cark it, it is just vibrating'. At first I thought it was my phone vibrating but I thought, hang on, your phone is in your pocket, and it vibrated again and I thought oh this is not very nice... it is a really unusual feeling 'cause it came from the inside, quite an unusual feeling. (Tina)

This behaviour from Tina's device was unprecedented. She returned home and contacted her electrophysiologist for advice as,

I didn't know what that meant... I said to them 'it is like I am getting a phone call but it is in my chest'. That is the first thing I thought of, but I said 'I don't put my phone up there' and they were all laughing. (Tina)

After several attempts at manual device downloads from home Tina went into the electrophysiology clinic where they established that,

The place that makes them, they had changed the frequency or the level of the wires so they were at 400... and now they had dropped them down to 300 but 'cause mine was still set at 400 they vibrated. (Tina)

Three of the 14 women in this study experienced device related issues, not associated with the initial implanting procedure, with another women undergoing further investigations at the time of the interview to establish if she also had an emerging problem. Device related issues can be life threatening and both experiencing them and managing them can increase the women's risk of physical harm, of which they were aware. However, it is also disruptive, impacting on the women's work, household and child care, as three of the four women referred to here were caring for dependent children. Issues often occurred at short notice and, if surgical management is necessary, it occurs out of the women's district, at a tertiary hospital, adding to the disruption. Issues were all unexpected and the women reported feeling fearful and uncertain about how to manage with the acute problems, although they appeared resilient.

Effect on other healthcare experiences

Having an ICD can impact on how women receive and experience other aspects of their health and healthcare services. Kate was pregnant when she had her cardiac arrest. She felt her pregnancy delayed her eventual treatment and discharge home with an ICD while the medical team evaluated the best way to manage her care to allow a safe delivery of her baby. It was intended that Kate would deliver in the tertiary hospital as this would allow the electrophysiology specialists and neonatal support services to be involved if required. However, Kate found that her labour would not wait for these plans, explaining,

It was already planned, after I left hospital, after my operation, that I was going to be in [tertiary hospital], to have baby. That they were going to fly me to [tertiary hospital]

straight away 'cause they wanted to have everyone there just in case. But no one got to do anything, because my son was coming whether people were ready or not! (Kate)

Lisa made the decision to avoid future pregnancies after her cardiac arrest and ICD. Following her arrest it was discovered she had Long QT syndrome, a genetic disorder that increases the risk of lethal arrhythmia. Considering medical advice and recalling how her cardiac arrest made her feel about the effect of dying and leaving her children, she regretfully opted to have no further children, reflecting,

I would have loved more children, actually I wanted eight. I did want more, and I thought hummm, no, and then going back to having my cardiac arrest and how I felt with my young family I thought, no that is not ok! It might make it activate... so yeah I hummed and haaaed and agreed to get it done. It wouldn't have been fair for me to leave the baby if I ever activated, which I have never activated but I thought no that is not very nice. Actually looking back now I don't regret it 'cause I have got to enjoy the ones I have but at the time I was like I want more kids, but yeah no I don't regret it now. (Lisa)

Having made the decision to have no further children Lisa evaluated her family planning options and chose the surgical option of tubular ligation as the appropriate contraception for her. However, equipment used during surgery can disrupt cardiac device function, requiring an electrophysiologist to change and check the device settings before and after a surgical procedure. Although Lisa's local hospital had acquired an onsite electrophysiologist, at the time of her surgery this service was provided every few months by a visiting clinician from a tertiary hospital. Lisa highlighted this information during her pre-operative assessments for this surgery, saying

They were going to do it and I said 'no', 'cause they didn't have a clinic here, 'cause I said to them 'you need to get the pacemaker clinic to turn me off', and they said 'oh why?' 'Because there is machinery in there that can interfere with it'. It blew me away that they didn't know about it, they said 'are you sure?' and I said 'yeah, you can ring them'. (Lisa)

Lisa felt that medical knowledge about her ICD in other specialty branches of healthcare was lacking. She had to tell health care staff of its presence and highlight potential problems and solutions for them. Lisa had intentionally sought knowledge about her device and felt a little disconcerted but also proud that she knew more than the doctor in this story,

I read everything they gave me, everything, and things I didn't know I would ask the nurse. So that is how I knew that there are things in theatre that could interrupt the pacemaker, and I just felt so cool when the doctor, when she said 'are you sure' and I said 'pretty positive' and she came in and said 'you are right!' and I said 'I knew it!'
(Lisa)

Lisa's ICD, therefore, caused a delay in her elective surgery. It had to coincide with the visit of an electrophysiology clinician, and the surgical booking clerk then waited to fill a surgical list with other patients with cardiac devices requiring this service. Lisa found this delay frustrating, saying,

That was what I found hōhā [a pest], 'cause I wanted that done straight away and it was recommended 'cause of my Long QT that I don't have any more children... Because they found out that I just couldn't go straight into theatre, I had to be stood down and wait until there were three or four other patients with pacemakers. Until it was worth them coming down, that got put on hold. They weren't going to come down and turn me off, I think on the day I got done there was about four of us and we all went in, I found that [delay] a nuisance. (Lisa)

Tina perceived elective surgery as unobtainable for her. She was a similar age to Lisa and also had a secondary prevention ICD but she also had a painful chronic inflammatory condition. She reported tearfully,

They won't operate for anything, they won't touch me! I get a real sore jaw and if they could scrape out in here, but they won't touch me. They won't touch me which I think is rude. 'Cause I've heard of other people who have had things and they have to get them to come in from [tertiary hospital] now, and they have to turn off the defibrillator or something and then do everything. They won't touch it anyway - so it is no use telling them. Sorry, (crying given tissues), it just makes it hard. Yeah, (blowing nose). Sorry, I don't normally cry. It just makes me feel that I am not worth the trouble - it is just like, you know, they just do whatever, to uhmm, you know, so other people with [this inflammatory condition] they get all this stuff! (Tina)

As Tina was aware of others with either an inflammatory condition or an ICD who were able to access surgical services, she was upset that with her combination her options seemed limited. She put up with severe chronic pain from her inflammatory condition, without anticipating any end to the pain. She no longer reported it to her specialists because she felt it was hopeless and

not worthwhile. While older than Tina, Beth also had a similar inflammatory condition. She did not report such widespread pain but, unlike Tina, she anticipated surgical options for this in the future. She reported checking that her device was compatible with surgery before receiving her primary prevention ICD, reporting,

It would probably be more of a worry if I have to have an operation now, my hip is not good... I checked that I got one [ICD] that was suitable to have an operation. (Beth)

Beth had not yet discussed surgical options with a surgeon or anaesthetist to confirm whether or not surgery would be possible, as she felt her problems did not yet require a surgical option. But her philosophy was that an operation would be a small risk worth taking and that, in theatre, she would be closely monitored with highly trained healthcare workers present. She said,

It is only preventative so if you have a cardiac arrest and are under anaesthetic then they just have to manage that the best they can. Yeah I am not a person that worries, I think that they are professional people who have training, I'm in their hands, and that is life. (Beth)

Medical imaging for testing purposes and diagnosing disease is limited by the presence of an ICD. It is estimated that up to 75% of those with cardiac devices will develop an indication for Magnetic Resonance Imaging (MRI) scans due to their medical co-morbidities (Brignole et al., 2013). While some new model devices are now being manufactured from materials that are compatible with MRI scans, this is not the case with most devices. Potential adverse effects of an MRI on an ICD/CRT-D include, heating of the electrodes, inhibition of pacing, promotion of tachyarrhythmias and programming disruption (Kalin & Stanton, 2005; Samar et al., 2016). This type of scan gives access to specific types of information about the body structures and functions, so not being able to have an MRI could limit diagnosis and management some health conditions. However, these scans are slow and take place in a noisy confined tube, so Fay, who has had many MRI's due to her structural heart disease, was ecstatic to learn that she could have no more MRI's, laughing happily while saying,

I don't have to do anymore! I never ever, ever, have to have another MRI! (Fay)

Other diagnostic tests may become technically more difficult and uncomfortable, as Rose found when getting mammograms done. She reported,

Jeez, that is horrible, I go every two years, I've just had one, so they have to try and take the mammogram without that [ICD] showing up and it is awful, they are poking and prodding. (Rose)

Most of the women interviewed took prescription medication to suppress arrhythmias, and/or to treat underlying cardiac conditions or co-morbidities. For several, their cardiac arrest and ICD marked the start of this course of treatment. Nora explained that her cardiac arrest highlighted underlying ischemic heart disease of which she was,

Completely unaware, wasn't on any medication, now on about six, nine tablets, that's a big change. (Nora)

Gail wishes she was completely unaware of some things now. She was put on Amiodarone (an antiarrhythmic medication) after having two appropriate shocks, to try and reduce her arrhythmias, so the device did not activate again. She understands that Amiodarone has toxic side effects which she is being monitored for and eventually her cardiologist wants to try taking her off the Amiodarone. Gail said,

But he hasn't got there yet and in the mean time I am quite happy, I just take them. Yeah, so I would hate to go off them and have this jolly thing happen [shock] again... He did say that I would have to be psychologically ready for it [amiodarone reducing], but he did say in six months. Well that six months is gone, but once again had he not made that statement, had he not said that to me, I would have been quite happy to knock off the pill, but once again that is putting the negative in, better not to know. (Gail)

Mere appreciated the opportunity to work with her cardiologist and GP to find an optimal medication regime, feeling that she had "a role in decision making" and "could have a handle on how it is still going". For example, Mere reported that she took only occasional Frusemide, (a diuretic medication) that she found was debilitating, affected her lifestyle with "the need to pee, and made her feel really cold". Pam also describes negotiating her medication and experience of them with her doctor, revealing,

He did want to take me off frusemide. But I was a little reluctant to come off it, 'cause it gets rid of excess fluid in the body and I have trouble with my ankles swelling, 'cause I work on my feet my ankles get quite puffy. But he said frusemide is not good to be on permanently 'cause it affects your kidneys. There was a little bit of backwards and forwards last time but I am still on them at the moment. (Pam)

Frusemide was a medication spontaneously referred to several times by the women interviewed. As a diuretic it is commonly used in the treatment of heart failure, and therefore cardiomyopathy, which are two conditions that increase the risk of cardiac arrest and are indications for primary ICD insertion. Ana also used Frusemide and, as she lived in a small rural town, this impacted on her accessibility to healthcare. For example, electrophysiology clinics and some cardiology clinics are based a couple of hours drive from her home town with almost no available public toilets between. While the hospital provided a free shuttle to the hospital, it still made getting to her clinic appointments more difficult. She explains,

As far as getting backwards and forwards, so I have got [two months] until I can drive again, so that is the only reason I have had to go on the shuttle, 'cause he [elderly husband] doesn't drive long distances. So the only thing with the shuttle of course, I either have to stop my frusemide or hope like heck that I don't need to stop before I even get out of town... you can't even get out of town you know and you need to go [toilet]. (Ana)

Rose also commented on the financial burden of managing the medications used to treat her underlying cardiac condition and reactive depression since her ICD. She lost her job as a result of the ICD insertion and said,

All the offshoots, the expense of. I have blister packs because I have so many tablets to take each time. So you are paying out fifteen dollars a time for blister packs and you know you go to the doctor, so my first visit to the doctor at the beginning of the year is \$90 in pills. So that is a lot of money and you know I have to go three monthly. It's no good ringing up for a script 'cause you've got to come up and get it, so there is all those things... the associated costs. (Rose)

However, not all the women interviewed were on regular medication. Several had not seen a cardiologist regularly since their ICD, and others were able to have infrequent contact with their GP, like Lisa who said,

With my doctor, I was on care plus and quarterly [visits], but now just every six months... 'cause other than the pacemaker I am healthy. (Lisa)

Genetics: effect on health experience of family

For some of the interviewed women, the underlying cardiac conditions identified around their cardiac arrest and subsequent ICD have an inherited or genetic component. This

impacts on the healthcare experiences of their families, as some other members may have been offered the option of preventative testing for this condition. Lisa discovered she has Long QT syndrome, a genetic disorder. She explained that there are several strands of this and they were unable to identify which strand she had, which would have meant familial testing could be done with a blood test. Therefore she “had to get my kids screened” as they became old enough explaining,

My children have all done the treadmill. My kids have all been screened and cleared except him [pointing to youngest]. He has been tested but he is borderline and so is not saying yes or no and he has sent it away to another doctor who is going to sit on the fence as well. So my son, he just has to stay away from anything adrenaline based, so they are sort of sitting on the fence for him. (Lisa)

Lisa’s extended family was also offered screening but most declined, with Lisa saying,

My mum was the only one who voluntary got tested and the others had to volunteer and they said ‘no, I would rather not know if I have got it’. So my brothers and sisters didn’t get tested, only my niece, a couple of my cousins got tested but the rest didn’t want it done. (Lisa)

It is interesting that many of Lisa’s adult family members declined to be tested, given that Lisa experienced a cardiac arrest and another sibling died from one, both aged under 40 years. However, when researchers approached Enid to do familial testing, she discussed this with her family,

We all agreed as a family, because our mother had a heart problem too and we thought it might be good to do a family tree to see if it is our family, we agreed, but I haven’t heard back and they were going to keep in touch... but we have never heard from them. They have never followed it though, but if they do we are ready to go through with it. A lot of the kids decided to go to their doctors to get checked and get done, mine did it. (Enid)

Independently organised testing was also what Nora’s immediate family chose to do.

They discovered that I have an inherited heart defect so, when I came back home, I’ve got three sons and they’ve checked themselves out and four sisters and they’ve checked themselves out, they are ok. (Nora)

Having an ICD impacts on all aspects of a woman's healthcare; childbirth and family planning, the experience and access to diagnostic testing and the experience and opportunity to undergo elective operative procedures. For several of the women receiving a secondary prevention ICD, their cardiac arrest was the first indication of ill health. For them it was marked change in their experiences, characterised by increased contact with medical professionals, pharmaceuticals and medical technology. All the women experienced this post their ICD, along with the financial cost associated with this increased contact.

Experiences around driving

Driving was the biggest practical issues raised by the interviewed women, and therefore will be analysed in detail. This sub-section will cover legal requirements around driving and the choice made by the women regarding whether or not to adhere to these. Issues around driving including a self-reduction or limitation on driving behaviour, and the negative psychological effects that the women associated with a restriction on their ability to drive. Many women experienced issues with alternative transport, which also caused difficulties with planning activities and engaging with the wider community. This section will also reveal how these women felt about being allowed to drive again and their fear of a further driving restriction in the future.

Legal requirement

Of the women interviewed, twelve held drivers' licences and two did not drive. In New Zealand the New Zealand Transport Authority (NZTA) has control over the driver's licencing system. In order to ensure drivers are fit and competent to drive, there are a set of medical fitness to drive rules around what conditions under which driving should cease. Currently recommendations state that, after a cardiac arrest and ICD insertion, there is a six month stand down period from driving, and a further six months each time an ICD fires. For a primary prevention ICD insertion the recommendations are at least two weeks of no driving, but these women were told six weeks (New Zealand Transport Agency, 2009).

Suddenly being unable to drive was an issue raised often by these women, impacting on many aspects of their experience of having an ICD. According to the NZTA guidelines the intention of these restrictions is to protect the public if further cardiac events occur and control of the car is lost.

Complying or not or early permission

All women were informed by medial staff of the driving restrictions when their ICD was placed, but driver's licences are not removed and no notation is made on the licence database in the first instance. If the women's medical practitioner discovers they are driving against advice they are then required to enforce the restriction by writing formal letters to the licencing agency and individual concerned. However, in the first instance it is up to the individual to comply with the instructions. The level of compliance and understanding of the fitness to drive instructions varied amongst the women. For example, Vera had had multiple shocks from her device, although none in the last couple of years, therefore she explained,

I am allowed to drive if I want to, but because of the quickness of how fast these things come over I prefer not to drive. (Vera)

She had followed the non-driving period previously and now, even though she was legally able to drive, she generally elected not to. As she had always lost consciousness very quickly before each of her 15 shocks, she felt less safe when in charge of a car, although if the situation required her to do so she was prepared to drive. She explained,

I can't drive for six months whenever I have a charge [shock] but now I haven't had one for a couple of years, so I could drive. If [husband] was in hospital for instance I would have no qualms about driving over to visit him, but driving around the village here I would rather leave it to him. (Vera)

Jill also followed the instructions not to drive for six months after her cardiac arrest, explaining,

Yeah I have heard of people that said 'oh sod it and drove anyway', but I was told not to and I didn't. It was hard, when I said to them I wouldn't drive, I didn't, there has got to be a reason, but I didn't realise how bloody hard it was! (Jill)

Tina, too, found the non-driving period to be very hard to manage. She enjoyed driving and found it difficult to let go of the freedom and control it gave her. She followed medical instructions, but examined them closely and realised they disallowed her driving on a public road only so she spent some time in her car driving around her own urban property.

I did drive my car around the house [laughing]. Just drove the car around the house. I was allowed to drive, just not on the road. The neighbours thought I was really weird, just driving around in circles. (Tina)

Lisa managed to adhere to the requirements for several months by calling on the assistance of her extended family connections, as she was the only driver in her household. However, she found that this was putting extra stress on her family network and still made organising her household with several young children very difficult. The demands of maintaining her household and caring for her children eventually resulted in her admitting “*I snuck around*”, saying,

My niece was actually driving me around for a couple of months but it was taking a toll on her 'cause one kid needed to be here, another kid needed to be there, so I actually started driving myself, I mean what cop is going to come and they are not going to that level of detail. So yeah I was driving myself or my mum, or biking, 'cause my partner doesn't drive [his own medical restrictions] so he bikes a lot, so he biked to town and did whatever I couldn't do. So yeah it was hard, but luckily I have got a big family, so I would ring them up and say can you come and pick me up or can you take my kids 'cause they have got to go here. (Lisa)

Pam also choose to drive against advice after her cardiac arrest. She explained that public transport was too expensive and inconvenient. She rationalised her decision by saying she was a safe driver and not on medication for her heart, explaining,

I have to drive, it is too expensive to get the bus, two trips each way to get to work and considering I didn't have a heart attack and am not on any heart medication I decided I would drive. It is something I considered and have undertaken to do myself and I am a perfectly safe driver. I know they told me six months but I can't possibly do that 'cause it was costing me 50-60 dollars in bus fares, you know, and I just had to give it away and just go in the car. (Pam)

Rationalising like this negates the intent of the driving restrictions, and does not take into consideration what would happen if another arrhythmia occurred when she was in charge of a car, and fails to factor in that she did also not expect her first arrhythmia. Ana also had a cardiac arrest but had also had several shocks from her device, losing consciousness each time. However, she also rationalised her decision to continue driving in her local rural town during the restricted timeframe, saying,

I look at it from this point of view, if there is only me in the car I can't see anything wrong with it, but I would never want to put passengers at risk by driving when I know I

shouldn't be. So I went down to [outside rural town] on Sunday, to an Iwi meeting, but I went with somebody else, because I didn't feel safe by myself. (Ana)

Beth was very annoyed that a six week driving restriction was not mentioned to her before she chose to get a primary prevention ICD. She only discovered this afterwards and she found it particularly difficult due to the timing,

It is a nuisance because I had mine around Christmas and I'm the only driver in the house and it was Christmas! I did actually tell [cardiologist] that I was annoyed, and oh, you know, he didn't seem that fussed, but of course it didn't affect him did it! (Beth)

However, after persevering with her doctor she reported getting an earlier clearance to drive, going on to explain,

Mine was cut down because I grizzled about it, but with my husband not driving... (Beth)

Enid also received advice from her GP to drive earlier than the guidelines suggest after her ICD fired. Her GP recognised the importance of her workplace and her job to Enid, and suggested Enid drive, but only to work. As Enid said,

When I had that slight mishap [GP] suggested that I only drive to work. Take myself to work, because she knows I enjoy my job and, well, she advised me, so for a while I was only driving to work and I wasn't driving nowhere else. (Enid)

Issues with driving limits

Driving longer distances was still something Enid avoided although she was no longer restricted. Mainly this was to avoid being on her own in remote locations, although this restricted her ability to visit family in her home town,

I don't go on my own anymore. I used to, my children, we all lived in [rural town in district] you see, and I used to just get in the truck and go over there and it didn't worry me. But now I make sure someone is with me, just for that thing in case it happened and I was on my own. (Enid)

For many women the effect of the driving restriction was often to confine them and narrow their world, as even within their own town areas became less accessible. This was not such an issue for Mere, as following her CRT-D implant, she only had a “*short period off driving*”. While she lived in the country 30 minutes from town and an hour to the nearest sea shore, bush or flax plantation, she was supported by friends to get to medical appointments,

recreational and cultural activities. This was important for her as she was a “*great believer in Rongoā [herbal medicine]*”. Mere has made medicines for her family for many years and particularly valued time in the bush to connect with nature and collect medicinal plants. Mere felt fortunate that her friends enabled her to continue with these healing activities through her driving restriction.

Jill describes how the limits imposed by the driving restriction made her feel. She initially experienced depression after her ICD implant and felt this confinement did not help, saying,

Not driving was the worst thing. I shouldn't say it was worse but I hated it. It did my head in, shocking, it made it a lot worse. If I could have had my independence, I'm not talking about driving to [next town] or driving to [distant town], but even just driving 2k down the road to the beach, it would have helped me immensely. It drove me mad it really did, not being able to drive, that was the biggest, one of the biggest things for me, not being able to drive. (Jill)

Jill had a small dog which she could only walk around her suburban block. Her physical condition and the driving restriction ruled out the beach for her, a more mentally uplifting area 2km away, and no public transport or taxi will transport pet dogs. She continued,

It really was hard, I couldn't take her [dog] out to the beach... So it was another block on my brain, now I can drive I take her down to the beach and go for a long walk and don't even think about it... Yeah I think I would have got over it quicker if I had been able to drive quicker... It drove me mad it really did, not being able to drive... 6 months is just too long. (Jill)

Rose was also effected by low moods post her cardiac arrest and ICD. She felt strongly that the driving restrictions and the limits this placed on her life contributed to her depression. It resulted in the loss of her job and increased her social isolation, giving her ample time to dwell on her ICD and the following restrictions. Rose had previously had a myocardial infarction (MI) with a few weeks off driving after that, a cardiac arrest where she received no instruction to stop driving and so didn't, before having a further collapse and an ICD. She felt that,

The ICD was even worse than the arrest. When I came home after the arrest I was just able to get up and carry on. I did have the distraction, 'cause they didn't say you couldn't drive. They did with my first one, after first my MI, said I couldn't drive for six weeks but they didn't tell me that the second time so I just drove... [After the ICD] I

couldn't do anything, I was stuck at home during the day by myself... with [husband] working nights and sleeping all day it was a really lonely time. (Rose)

She clarified this feeling by then saying, that as well as this loneliness, it was her loss of independence that she found emotionally difficult,

Because I am an independent person I just felt like everything had been taken away, my whole life had just been turned around. It was scary it was a scary time, and having that independence taken away was real tough, really really tough, 'cause I hate having my wings pruned. (Rose)

Issues with public transport

As discussed earlier most of the women continued to manage their household and caring roles. However, not being able to drive made these tasks more challenging. Seven women had no other driver in their households, and, as Rose found with her husband working night shift, even having a driver did not mean that they were available at convenient times. Women relied on extended family and friends for some transport, but this was not always available and, over six months, these resources could become stretched as Lisa found earlier. Public transport in the women's district consists of a bus service or private taxi services, but these both had their limitations. Pam had already referred to the cost of using the bus regularly to go to work but also found it time consuming as it added 45 minutes each way to her commute, resulting in increased fatigue. This contributed to her decision to commence driving, as she explained,

I work from 9 to 5.50 so the time I get home it was 6 o'clock and on the bus it was worse, 6.45pm, I was quite tired initially... (Pam)

Gail had a total of eight months not driving. She learned to use the bus eventually for outings with her primary school aged child. Bus travel was free for Gail, as she is over 65 years old, unlike Pam who found it expensive, but like Pam she also found that bus travel was physically demanding, and involved more time spent travelling that she could physically cope with.

If you are going down to catch the bus, there is the time and then you have all the issues with the weather... I still catch the bus, which I had never done before in my life. But initially I couldn't walk down to the bus stop, but now [child] and I, we go and catch the bus. It is free, and I absolutely enjoy it, and so does [child], he wants to be a bus driver, so we still do that, so we changed because we had to. (Gail)

Beth felt that bus travel would not meet her needs. She had an inflammatory condition and bad hip that limited her mobility a little, making getting to a bus stop difficult. Additionally, post her ICD, she should not have been lifting and shopping requiring carrying bags home, saying,

Can't walk miles and miles. If you consider how far I would have to walk and then you would have to carry the things. It doesn't matter whether you have [inflammatory condition] or not, groceries are heavy, you know, you can't live on featherweight. (Beth)

Many women occasionally used taxis. However, this still required a frustrating wait for the taxi to arrive each time, as Jill expressed saying,

I just couldn't get out, I couldn't, I got sick of waiting for a taxi to go to the supermarket, I thought it is only two minutes down the road! (Jill)

Taxis were considered to be expensive, a factor that was important to Gail who abruptly retired post her ICD and subsequent shocks, affecting her finances. She obtained access to a council subsidised scheme for half price taxi fares through a family member. She regretted that this information was not given to her by hospital staff. As it was so helpful to her she wished it was available to others in her position.

I was very fortunate because my [family member] who is a [chronic disease specialist] support person and she came and did the assessment for me to have half price taxi fares. Now no one told me what help is available and how to get it, so no where was I told that... maybe it should have been a heart person who said, you can get these half price taxis and these are the steps you go through. (Gail)

For Ana, who lives in a small rural town her transport options were more limited. There was no bus service within the town, just a bus going through to the next town once a day. Ana explains her town's services as,

The only bus, leaves here at 10.30 and on the way back it gets in at 3.30, but that is the only bus service we have. Plus there is the community bus, like a van for people who want to go for a blood test or doctors appointment... You depend on someone else, which is hard to find if they are all working. (Ana)

These more limited services did not affect Ana as "it is ok locally,' 'cause I can drive around locally". For trips to the local hospital she found the free shuttle service to be lengthy, with uncomfortable seating, and difficult to manage with her diuretics, as well as the whole day being spent at the hospital. She preferred to arrange her own transport for these reasons as

then, after her appointment, she could go shopping, making the trip more productive as well as pleasant, saying,

I try to do is try to find an driver, a safe driver to drive me through, and I find that good, 'cause we can go shopping, 'cause you have got nowhere really to shop here, you have a better choice and you can spend the whole day there. (Ana)

Basically not being able to drive made the women's lives harder. Finding ways to cope with the restriction took time, drained their physical and financial resources. Increased planning was required for everyday activities and their options were limited around how to manage this. As Gail reflected,

Anything you did, it became an added thing, that you had to think, how do you get there and the time. So anything that you wanted to is made harder. (Gail)

Gail goes on to give the example of getting her young primary school aged child to and from school safely, explaining,

I had to work a roster. I had one parent and one friend of mine came at a certain time Monday afternoon, and I did use the half price taxi fares and which were very helpful. I mean it is only a little distance, but when you are not physically well enough to go there and walk back. Sometimes I would walk there and taxi back. So there had to be a roster of actually getting him to school, he could go to [after school care program] and they very generously came and collected him some mornings and took him to school. (Gail)

Tina was fortunate that, during her prohibited driving period, her daughter acquired her learner driver's licence. While this gave Tina's household access to a driver again, allowing her to adhere to some of her usual routines, it was still stressful, as Tina said,

My oldest, she had to drive me everywhere, poor kid, 'cause I am one of those people I always do my groceries on a Thursday and I like to get there by a certain time. She likes to sleep in but had to get up and take me to the supermarket, 'cause I have a system but I lost my independence, and had to rely on everyone else, so I HATED it! (Tina)

Difficulties planning activities

As well as routine household activities and work, not being able to drive meant the women's social activities also became more difficult, contributing to their loneliness and low mood already discussed. Gail believed it was not coincidental that, regarding her counselling sessions,

“the final one was the first day that I was able to drive!” Since Gail had begun driving again she had worked on increasing her social interactions, saying,

Not being able to drive created all sorts of things... What I have done now, is I have rebuilt my social life, I recently joined grey power, I thought no I'll go and have a look, it is being amongst other people, that one meeting was great and I am going to go again... I am singing again, now that is really good. (Gail)

Driving again

For the women who adhered to the driving restrictions, being able to drive again was an important marker in their recovery, representing normality and freedom. Jill described how she felt after getting clearance to drive again after her community cardiac arrest and ICD, as,

Wicked absolutely wicked... I had to do a test for [electrophysiologist] the night before...she rung me at work and said you can DRIVE and I went YES! All the boys in the back were laughing, 'Christ warn everybody she is back on the road!', but it was neat just to be able to. I felt like someone had said you have won lotto here is a million bucks, and I actually felt a lot better because I could drive my car. (Jill)

Gail was a little nervous and felt out of practice when she first returned to driving, making a very short trip her first day, explaining,

Because you have had all that time off and 'cause you are using different muscles that you haven't used, the first day... I got around the first block and that was it! I didn't want to go any further... I hadn't been driving for 8 months, I think, it was a physical thing as well, as a mental thing... Now of course you just get in the car and go. (Gail)

Fear that it will return

The impact of not being able to drive was so significant for some women that they dread an arrhythmia and ICD shock, not for the unstable rhythm but for the consequences of the shock on their driver's licence, Tina sums up this attitude with,

The thing that gets me is, that if it goes off I would have six months with no driving again. Now you think, god, if it goes off again, I can't do anything! (Tina)

Positive value placed on interpersonal relationships

Interpersonal relationships were discussed by all the women, as being of major importance in their ICD experiences. These relationships were key to how they managed to deal with the implications and effects of their ICD. Strong positive interpersonal relationships were a source of practical, emotional and social support, and provided an impetus for these women to strive for positive behaviours and emotions to better nurture their relationships. Interpersonal relationships as a source of strength and motivation was recognised and valued by all the women living with an ICD. Within this theme there are several sub-sections addressing various interpersonal relationships identified as influential. These sub-sections include familial relationships with partners and parents, independent adult children and dependent children. Outside these family relationships, relationships with work colleagues, medical staff and friends or peers were also identified as important to these women and will be addressed.

Relationships with partners

Nine women lived with a partner at the time of the ICD implant and all remained in that relationship at the time of the interview. However, many of these women spoke of how the nature of their relationship with their partner or spouse had altered as a result of the ICD. For some their partner's role in the household had changed, often to include more housekeeping tasks than they had done previously. Ana explained how, when she first arrived home very debilitated after a secondary prevention ICD, her relationship with her husband changed enormously as he was required to provide a lot of physical support,

I was bedridden, I couldn't get out of bed, I couldn't walk, even when I came home... my husband was the full timer caregiver during the night, and he was 87, and it was a bit hard.... I thought what my husband had to do, cause he would sleep in the other room and as soon as I started to move he was up and he could have been up about half a dozen times in the night just to have a look and see if I was alright or did I need to go to the toilet, you know, or what was the problem. (Ana)

In addition to physical support and caregiving, he also provided emotional support which helped her to cope with this new phase of disability and recovery,

There was many a time when I said to [husband] 'oh I've given up!' Several times during the year, I said 'I just can't bear this, this is too much', and he said 'oh no, no, this is what we will do, we will try this' and 'we will try that'. (Ana)

Vera also experienced a marked role change within her marriage, associated with decreasing physical capabilities. As well as her cardiac condition and ICD, she now had a progressive muscle weakness resulting in less strength and stamina. She described her life before her ICD and failing health as active, independent and in charge of all household tasks. Afterwards, her role in the household was quite different. She said,

It is quite interesting, the kids are fascinated, it is two totally differently lives, I mean [husband] can cook a beautiful roast dinner now but before he couldn't even boil an egg, I don't think it would have ever occurred to him. He does all the shopping now too.
(Vera)

However, as was reported earlier, most women continued with their established household tasks and roles once they returned home with their ICD. Although Rose acknowledged her husband that “he’s been the housewife”, she stated that he was recovering from an operation at the time of interview that “I’ve had to step up and do the heavy lifting”, and her old household chores again. Many women valued the sense of normality that fulfilling these roles entailed and the independence they felt when able to do them. For example, while Vera appreciated her husband’s practical support she also appreciated that he allows her to make independent choices about what aspects of the role she could still manage, saying,

No, he has been very good and coped with it very well. Doesn't mother me or anything like that, makes sure I don't overdo things, but he doesn't say 'you can't do that'. (Vera)

Enid also valued maintaining her autonomy along with her husband’s support, as demonstrated in a discussion with her husband after her ICD fired,

My husband and I had a talk about the situation and I said that may be that they could give me a different job at the school, cause of the stress you know, so we talked about it 'well' he said 'it is up to you, you just see what is a better option.' (Enid)

Lisa reported on her partner’s increased anxiety and awareness after her ICD, particularly concerning her expanding her activities,

He was worried, because I was cheating and doing things and I said 'look they haven't rung me', and I think it took him longer to adapt.....he would say 'hang on, did your doctor say you could do that?' and I would say 'oh they pick up everything on there [remote monitoring] anyway, so don't worry about it'. (Lisa)

The women's partners often coped with their increased anxiety about their partner's health issues and ICD by increasing their surveillance of their partner and gathering information and knowledge about potential issues. Recognising her husband's stress, Rose's understood why he had become 'extra vigilant' of her health and issues, acknowledging that,

He is terribly protective of me, so if I say I've got a bit of pain he's up there and 'no come on we'll sort this out and dah laa laa'. He's very protective, 'cause he's been through a lot, he saw me arrest in A&E and that was horrible. (Rose)

Rose also felt that, to assist her husband in supporting her, better information and support could have been offered to him, saying,

I gave him the brochures and said 'here, read that', but it would be good if there was something available for the partners to sit down with somebody, and say 'now this is what happened and this is what you might expect or you might not, everybody is different but this is what you can do'.....'cause [husband] would have really appreciated someone to sit down and talk to him about it. (Rose)

Kate's partner, however, pro-actively sought out information for himself, which helped him to feel more secure and in control of possibilities. For example, prior to taking their premature baby home, he attended an infant CPR class (after demonstrating good CPR skills on his adult partner).

A few women became more dependent on their partners for emotional, practical or physical support. Having a partner around can also reduce personal anxiety for the women. Vera had had 15 shocks from her ICD and then CRT-D device. She blacked out with little to no warning prior to her device activation and over time has come to hate this happening in public if she is unaccompanied. She explained,

I don't like passing out, but I don't mind if my husband is there, he is going 'no, no just leave her she will come right it is only a few more seconds' and they think he is the hardest, harshest husband anyone could have, poor fellow. So yes it changed me 'cause I was the most independent person.....and all of a sudden now I am dependent on him. (Vera)

However, most women did not become more dependent on their partner after receiving an ICD. The level of dependence could alter over time, according to factors like Vera's increased number of shocks received, and like Ana with her changing physical condition. Fay

spoke about regaining her independence after receiving a CRT-D which seems to have successfully controlled her recurrent arrhythmias and ceased her frequent hospitalisations. She commented that she is no longer the “invalid” and her communication and relationship with her husband reflects this,

He is so happy that I am not going into hospital all the time, so relieved, as it was more of a worry for him and it got to the stage I wouldn't be telling him how bad I was, 'cause I felt like I was forever saying that I am not well today. Eventually he would guess anyway. (Fay)

Fay is not the only one who got to stop saying ‘I am not well today’. Despite an unpropitious start Ana regained her physical strength and this too had further altered her marital relationship as,

I am probably more active now than I was 10 years ago. He is home on his own most days.... so as I say he has to make an appointment with me as to when I am going to be here. (Ana)

However, when asked if receiving her ICD for primary prevention had impacted on her relationship with her husband, Beth summed it up as follows, suggesting that women in their illness relate to their partners in ways consistent with how they have always related.

I mean we have never been into drama you know, acting up, you know the thing is it depends on your relationship often, with your partner or your husband, because if you are pampered, then you are always pampered and if you are the one that has to be strong, then that's it.... You know somebody has to carry on. (Beth)

Relationships with parents

Having an ICD impacted on the women's relationships with their parents as well. Lisa experienced her mother's protectiveness towards her, when Lisa's mother's concern for Lisa led her to try to prevent Lisa from participating in a sporting activity that had been medically cleared for her. Lisa recognised and understood her mother's concerns, although she was a little frustrated by them, as she explained,

My mother actually went around and said I wasn't allowed to play so she was my biggest obstacle, but I could understand where she was coming from, she was worried. My mum hasn't processed it and she never will, and you know, fair enough. (Lisa)

Mere also found that her mother did not cope well with Mere's changed health status after she received a CRT-D for an iatrogenic cardiomyopathy post chemotherapy. Mere's mother became stressed that Mere was "no longer vibrantly active", as she had always been seen as "a strong leader". To reduce her mother's distress Mere reported forming a sort of substitute maternal relationship, initially for support, with an older woman whose husband had heart failure and an ICD.

Rose, however, found that it was not always helpful to have a similar health experience as a maternal figure. Her mother seemed to view her pacemaker for a slow heart rate as directly comparable to Rose's secondary prevention ICD, with Rose commenting,

My mum was very good..... but as much as I loved her she just about drove me insane. She was very, 'I've been there and I've done that' and she was great at turning it around and making it all about her. (Rose)

Women who cardiac arrested often thought of parents who had already died and reflected on their own mortality in relation to their parents'. Lisa said,

Lucky, my dad wasn't ready to see me, it wasn't my time. (Lisa)

Enid's thoughts on receiving her ICD also went to her deceased mother and her premature death,

Well, my mother died when she was 44 and I know that when I got this put in I thought straight away of that. I was 21 when my mother died you know and I think to myself, if only these things were there when my mother had hers, she might be still alive. (Enid)

In terms of support from parental relationships, the interviewed women talked mostly of their mothers. These relationships were complex, however, and not always seen as helpful.

Relationship with independent adult children

More frequently, the interviewed women spoke of receiving support from their adult children. Those with children living out of the district described the satisfaction of having regular telephone or skype contact with them and finding this contact supportive. However, women with locally based children really valued the practical and emotional support that their children were able to offer, especially immediately post ICD insertion. They spoke of adult children setting up the home based technology accompanying an ICD and assisting with transportation while the women were unable to drive. Jill regards her son as,

An absolute god-send, I don't think I would have got through as strong as I am today without his support, I really don't... I couldn't have got through it without him, he has been absolutely wonderful, he doesn't live very far away and I talk to him every two-three days and he comes around, so he has been absolutely marvellous. (Jill)

Rose described her sons,

They really are wonderful, and so supportive of anything that I do. The kids are great, I only need to ring them up and say come around will you, and they will. (Rose)

Rose and her husband, who was present for part of the interview, also agreed that after her cardiac arrest and ICD, their family relationships strengthened, bringing them closer to their sons. They attributed this to their children's realisation that even though "mum has always been there..... mum is not infallible".

Mere found that, for her, the hardest thing was telling her three adult children about this fallibility and her ill-health, explaining to them that "the window of mortality was shrinking, with a haze around it and would remain so". Conversations of this nature were difficult for the women. Mere revealed that, through her experience of talking with her children, she learned,

Not to talk too much, let them absorb, think about it, as they are intelligent caring people. I used to keep talking to fill the silence, now I know they like to sleep on it and mull over things. (Mere)

Mere also wanted to set a good example of how to handle illness for her children and community, therefore she found it important to stay strong. She was determined to be as well and strong as possible and was aiming to "not be an invalid". Vera was also aware and proud of being a positive role model for her children. She said of her adult children,

They have all got a different [medical] condition and they are all really good with it, 'cause they saw me with mine from 24 and just getting on with it, so they all get on with it. (Vera)

Several other women also needed to consciously decide against the 'invalid role', as their children tended to be overprotective when their mothers initially got their ICDs. The women acknowledged their families' concerns, evaluated them and made their own choices. For example, Jill said,

I got up and pruned that rose and [son] said 'what were you doing up there!' and I said 'it was a little ladder, I stood on it and clipped them'. 'Don't do that' (snappy tone). Very protective, but that is understandable too... I just take that, I know he cares, if I thought I was doing anything stupid, but I'm not. (Jill)

Some of the women's adult children attempted to modify their mothers' behaviour in other ways, such as actively encouraging a healthier diet. Ana noticed this. She described how, when her son visits,

He watches everything and when we go shopping he tells me what I should be eating. Well I am very cautious when he comes home, he will be here in a couple of weeks so I will cop it again. (Ana)

Ana's children have also tried to protect her from stressful knowledge about their own health. This proved counter-productive as, when she realised her son was not telling her everything, she worried about what else might not be being said, explaining,

Then he took a while to tell me. I think that was probably something that worried me for quite a bit, the fact that he hadn't told me earlier. (Ana)

While the women talked about family relationships as being strong and how they were able to rely on their adult children for support, Enid provided a reminder that the women remained parents with parental responsibilities. Talking about this Enid mentioned her daughter who, suffers from mental health issues and 'goes through a lot of bad times',

I say to her 'you're an adult now', but at the end of the day it is still us she turns to, you know, we are her parents for goodness sakes.... yeah we just help look after them and if anything happens to us they will just come, we are a pretty close family. (Enid)

Relationships with dependent children

Four of the women interviewed had young, dependent children. All four received secondary prevention ICDs. For them, the responsibilities associated with having dependent children had a significant impact on how they experienced and processed their cardiac arrests and ICDs, as well as how they related to their children. This subsection will cover the emotional impact of the ICD on this relationship, the effect on the practical demands of childcare and the need to just carry on with parenting. The women with dependent children particularly valued the time they can still spend with their children and acknowledge the impact of their dependent child's age on their experiences.

Emotional impact of the cardiac arrest and ICD on the relationship

Both mother and child surviving a community cardiac arrest mid- pregnancy is uncommon, so, for Kate, simply being able to have a relationship with her child caused additional complications and stress. She recalls recovering consciousness after her cardiac arrest and thinking immediately of her baby and her joy at discovering that,

My baby was strong, [his] heart beat was strong and that was the first thing I woke up to, asking, my baby, my baby, and yes his heart was beating and mummy's... so yeah, he is my little miracle, he survived it and so did mummy and we have been given a chance again. (Kate)

Lisa, however, was already a new mother to a baby and had several other children under the age of eight. When she had a cardiac arrest in hospital, she too focussed on the welfare of her children when she realised what had happened,

I was shattered aye, 'cause all I could think about was my kids, my kids, they were only young then, really young, so I was shattered. (Lisa)

Lisa spent about three and a half weeks away from home, most of it out of her district in a tertiary hospital. She had her partner and mother with her for support during this time and was very grateful that her sister just turned up at home and said she would look after all the children. Lisa had been reluctantly organising to split them up amongst family and friends. She describes some of the stress of this time,

They were going to hold me up there [at the tertiary hospital] for a while but I just cried and cried, and said I have got to go, I have got a new born baby and I don't care if I have to walk, I'm leaving your hospital. I said, I am going home, I don't care how you get me there but I am going home, with permission or not, that is how adamant I am, I haven't seen my baby. So they got me home right smart that day. (Lisa)

Kate also spent time at a tertiary hospital some distance from her home. She was there for several months and also had her partner with her for support. She, however, choose early on to have her young daughter, who had witnessed Kate's community cardiac arrest, brought to join them after a few days. She felt this was important for her daughter's sake, as maintaining her family unit and talking to her daughter about her experiences helped calm her. Kate explained,

Well, she wasn't coping, going through that trauma, and still wanting to know that mum was still here you know, so my partner ended up coming to get her...and they

stayed until I was able to come out. For me I would rather that she would be with us so she wasn't going though it alone. Even though my friends are really good, it wasn't the same. (Kate)

Tina's pre-teen daughter also struggled with the separation that her mother's hospitalisations required, as Tina recalled,

She does like trying to stay in the hospital with me though... she used to fall asleep with me in the bed... in the hope that the nurses wouldn't see her. (Tina)

This time spent away from young children, especially when the women were transferred to a hospital in another region, was emotional stressful for the children and the women, but for Lisa it impacted on her ability to bond with her new baby. Lisa found this particularly harrowing. She talked about returning home to her new born,

What was shattering for me was he actually sort of forget me, for three to four weeks after I came back he wouldn't come to me and that really shattered me you know...I had lost that thing with him, he just wouldn't come to me for a while and I found that devastating. And [toddler] wouldn't come and my older ones took it hard, so yeah it was intense. I wouldn't wish that on my worst enemy. (Lisa)

Practical care of children

In addition to these intensely emotional experiences, the women also had to initially consider how they would manage the practicalities of parenting their children. For example, when Kate finally took her prematurely born baby home at six months of age, she was concerned about how she would care for him. In the hospital the nurses had always given her the baby once she was sitting down and she had never picked him up herself. After the implant of an ICD there are initial restrictions and limitations recommended for how much movement and weight should be put on the arms. Kate worried she would not be able to lift or carry her baby, so was concerned about how she could properly care for him, although she quickly adapted once home. Lisa experienced something similar but the limitations on her caring for her baby were enforced by other family members and her ICD implant was more recent. She reported that, on her discharge from hospital, her input into baby care was initially rebuffed by female family members, which did not help the process of her re-bonding with her baby. She said,

I wasn't even allowed to hold it, my sister wouldn't let me, and my mum. (Lisa)

Just need to get on

However, despite initial concern and adjustments, having dependent children motivated the women to get on with life. Although retired at the time of the interview, Gail has been the long-term sole caregiver of a primary school-aged child. Post her cardiac event she had attended cardiac rehabilitation classes and commenting that,

I couldn't believe how all the men complained, driving their wives mad, but another woman who was older than myself [and I], we didn't have husbands so you just have to do it. She said 'it is alright for them', but we had no one else around so you just had to do it...I still think that with having [child] around I had to get up and I had to do things. (Gail)

Being the primary carer for children meant that caring responsibilities and household tasks continued and could not wait. Children still needed to be fed, taken to school, to sports and to be loved. Nora recognised the magnitude of this role when she chose not to take it on. Nora's son separated from his partner and he maintained sole custody of their two preschool-aged children. Nora explained how she would have liked to offer to step in to care-for these children but did not feel confident about being able to fulfil this role after her cardiac arrest and ICD, despite describing herself as active and healthy. She said,

I would love to go and help him, but I feel at 75 and this happening and he's at work all day and I feel with the kids on my own, I say what say I collapsed and they were there? (Nora)

Importance of having the time with your children

All the women with dependent children survived a cardiac arrest and value the extra time they gained, not solely for themselves but also for the extended time for raising their children. Kate identifies as Māori and felt strongly that well balanced Māori children need to be aware of their cultural identity. She articulated this as,

I want to see my kids grow up, so I can teach my language and identity to the kids, so they know where they are from and who they are. As so many kids don't know now, and this is not a good thing. (Kate)

Although Vera did not have dependent children, she commented that children are 'better off' if not left motherless at a young age. While she did not receive her ICD until her early 70s, as a 24

year old mother of several children she was diagnosed with a cardiac condition causing potentially lethal arrhythmias and given a limited life expectancy. She reported,

I was told to bring my children up very independently, to spend every penny of my husband's so his second wife got nothing. My doctor said, if you got an opportunity to mortgage the house and take a trip do it 'cause at 40 I would be dead. (Vera)

However at 40 she had a massive heart attack and cardiac arrest. The damaged muscle from the heart attack suppressed the arrhythmias she had been suffering, until a further cardiac arrest decades later led to an ICD. She focuses on her children and their youth when describing her near death experience, aged 40,

When I had the heart attack in the hospital I went flying up to the ceiling and I could see two nurses working on me down there, and I'm up here sort of shaking around and then I thought oh god [Son] is only ten! I'll die when he is twelve. And I went crash back down on the bed and the nurse with the worst bad breath in the world was pumping me, bruising me, so I said to him [Son] you saved my life, 'cause I was off otherwise! I had four lovely wonderful kids and I knew they would be perfectly alright without me, except the little one. He was only ten and I thought, twelve, he would do better if I could last till then. (Vera)

Age of children and support they provide

The age of dependent children effected the women's experience of having an ICD, not just in terms of how well they felt their children could cope with being motherless but also how supportive the children could be of their mothers. Tina lives with a chronic inflammatory disease that can limit her physicality at times. This contributed to her initial heart attack and her cardiac arrest a few years later. Tina feels that her teenage children have a really positive relationship with her and is proud of how they cope with her health problems, but she emphasized that she retains parental control of the relationship despite requiring their physical support at times. She said,

They are really good, they are really compassionate. My girls are fantastic, they know when I can't do things and they pamper me...My youngest was very clingy, and my oldest, she had to drive me everywhere. My kids have been great, they are just fantastic, they have helped me...My oldest, she can get really overprotective, I had to say to her 'it is alright', she goes 'well we are just worried about you', I said 'that is alright you can be worried but don't push it'. (Tina).

Gail, however, had to plan for the ways her child could provide support. After her cardiac arrest and device activation both occurred at home within a short space of time, she arranged to have a medical alarm installed so that she could train her seven year old child how to get help if he was worried about her. She felt that, under times of stress, pushing a button would be easier for a child than having to make an emergency phone call, although she explained how she had talked to him about how to do both. This sort of planning for problems was reassuring for both parties.

The responsibility of caring for dependent children after a life threatening cardiac event and subsequent ICD had a significant impact on the experiences of this subsection of interviewed women. The women appreciated that they were fortunate to be alive to continue to parent, and acknowledged the impact that this had on not just themselves but their children, both emotionally and practically. These women often had to quickly resume parenting responsibilities and routines, as discussed earlier. The women with dependent children truly valued the opportunity afforded to them to hold on to these relationships after surviving a cardiac arrest.

Relationships at work

Employment offered the women another opportunity for interpersonal and social connections, which the women often valued as a distraction from their health issues and an indication of normalcy. Jill explained that after her cardiac arrest and ICD implant,

You do think about what if it happens again, but I went back to work as soon as I was allowed, and that has really really helped because I am with people, talking to people. 'Cause I think if I was sitting at home thinking about it, it would be worse. (Jill)

After her cardiac arrest and ICD, Kate also found that it was good to be working, even though her return to work had been intermittent as she was initially occupied being a mum to her premature baby,

Good to be working as it took my mind off it, if just sit around and think about it, it is not good. Didn't want to sit and mope, but tried to do what could as best could. (Kate)

Gail also valued time spent in the roles and situations familiar to her from before her cardiac arrest and ICD, saying that eventually,

I just got to the stage that I just, I wanted to be with people who were well and do normal things. (Gail)

However, she also re-evaluated her work place after her ICD was implanted, identifying stressful relationships and situations present in this environment that were not beneficial, and she chose to retire. She said,

I was working when all this happened and as I say.... I am getting close to 70 right now, and I was working [in education] and I've actually let [that] go, 'cause stress was very definitely a big contributor. [The workplace] was extremely stressful, I wouldn't even do it today. (Gail)

Since her retirement Gail had done some regular volunteer work, which provided her with positive adult interaction and relationships, but in a less stressful environment,

I love that we are working with great people and being out with people and learning a few skills I haven't had for a while, but it gets me out and happy. (Gail)

Like Gail, Enid also had a community cardiac arrest and worked in education. She really enjoyed being part of her school community but she also re-evaluated her role there following a shock from her ICD, choosing to reduce the intensity and stress, explaining,

I still wanted to work there, because I like the kids you know, and it wasn't about the money because I've got a husband to keep me, but wanting to do, wanting to be available to do something, so they offered me the position I'm working in now. (Enid)

Having a supportive and accommodating employer, as Enid did, helped women to regain or obtain their employment, something that they really appreciated. Jill had a community cardiac arrest in her workplace and a colleague provided prolonged CPR. Her employers then held her job open for her till she was ready to come back, slowly increasing her hours and modifying her workspace to enable her to rest more while working. She acknowledged their support,

They have been really brilliant, absolutely superb, I couldn't have wished for better. I couldn't wait to get back to work. (Jill)

Lisa also has a positive relationship with her employer. She was approached by her current employer after receiving a secondary prevention ICD, through her community connections,

They actually approached me too knowing that [I had an ICD], knowing that not many people would give me a job in a hurry. (Lisa)

Her employer's understanding and ability to offer flexible support was also greatly valued,

My boss, she is actually amazing, like I told her that time they found I had a faulty lead, I had to ring her and say I can't come into work, I need to go have my lead changed, but she is aware of everything, 'no that is fine, well you will need a six week recovery, we will sort that out when you get back'. (Lisa)

This contrasts with the Rose's experience. She lost her job following her secondary prevention ICD as she was unable to drive for six months following the implant and part of her duties involved driving others. This greatly reduced her confidence and limited the scope of her interactions. It took her over a year to use a government assistance program to get back into the workforce, initially doing some volunteer work to get experience and confidence back before getting her current job. She also made a conscious choice to reduce the potential for stressful interactions and relationships when selecting her employment, explaining,

Being a [healthcare provider] was very taxing physically and mentally, it was very very hard work...[now] it's not physical, it keeps my brain ticking over, and that's great and that brought me back to thinking, hey there, where you're at the moment is not where you should be, and you need to get your life on track again. (Rose)

After receiving an ICD some women exited the workforce after re-evaluating their lives and the sources of stress. Other women chose to alter their job for something less mentally or physically stressful. One woman was forced to resign as a consequence of her ICD. However, other employers were very supportive and accommodating towards these women, seeking them out for employment, organising flexible return to work as required and allowing movement within their organisation, enabling women to continue their employment with them. Women recognised and valued their employers support and valued the opportunity to work. More than money, work represented normality, social interaction, distraction and an opportunity for women to feel valued as well. Those not engaged in paid employment often sought out voluntary work for these same reasons.

Friends and peers

Peers offered the women an opportunity to share and compare their experiences. Most women seemed to feel that their experiences were unique which could be an isolating experience, Vera felt like a local pioneer stating,

When I first got mine years ago hardly anyone had them. (Vera)

A few women had distant connections with other ICD recipients, connections that they often commented on with surprise at knowing another person with one.

My sister has a friend who she nursed with who has just had one implanted. (Nora)

Some women established informal contact with other ICD recipients. These women recognised however that contact on its own was not always helpful to them, but contact with the right person was. Beth's brother-in-law had an ICD but was not really someone she talked to and while Gail and Jill were related too and could also relate to receiving a secondary prevention ICD, Jill found,

I did talk with Gail about it, and there is another customer [name] who comes into work, she has got a lot more heart problems than me and she has got an ICD...she told me that ages ago... [customer name], is more like me, she is gorgeous, so I had a big talk with her about it as well. Yeah I mean I did talk to Gail about it but.... (Jill)

A couple of women were also able to reciprocate, providing information and support to others waiting for ICDs, like Lisa who had had contact with someone from her extended community network,

He actually came and saw me, I said 'it is not as bad as you think once you get over the fact that you need it and chill out'. (Lisa)

And Beth, who planned to share her experience and knowledge of problems,

I actually have a friend that is going to have one too, and I've told her that it doesn't say that [about driving restrictions], but I am going to give her the information that I have here...Well she only came back last week from the consultation...so I haven't got back to have a really good talk with her, but I will. (Beth)

This was not possible for everyone and some women really missed this lack of appropriate peer support and discussion with others who have experienced and understand some of the nuances of their situation. Rose was particularly clear on this point,

There was no one here, there was no support group, well there is I suppose if you're 80, 85 laughing, [cardiac companions club] they were meeting at the National Service Club, which you know... I wasn't 60 then! I thought no way, hang on a minute, I've got a lot of life left in me yet and I needed to talk to people in my age group or younger even... It was a really lonely process after I had this [ICD] done, because there was just nothing

here, absolutely nothing! You know, who could I ring, from that support group, that I could ring and say 'hey have you ever felt like this? or...'. (Rose)

While she identified a wonderful network of friends, Rose strongly desired conversation with other ICD recipients. Her friends were not able to draw her from her initial depression. She stated,

It got to the stage that I didn't answer the door, I just didn't want to talk to people, I just wanted them to go away...I had neighbours and friends come over and say 'if you want to go into town, just come over and ask', but I just wouldn't, but it was a really bad move, it would have been good really to go out and get out. (Rose)

Tina valued the practical support her friends offered to her and her family. She said,

Really good friends who have been there for me, and not just for me but for my mum and my kids, they were there for them and that is the main thing. They were making sure they were ok, you know my mum she doesn't drive so my best friend she was driving her into Hospital, backwards and forwards all the time, she was amazing. (Tina)

She also enjoys using humour with her friends around her ICD,

I've got real funny friends who go 'don't touch me you might shock us', or 'can you jump start our car', so they do have a lot of fun. I had a lot of fun too, 'so, no you can't pull it out of my chest to jump start a car!' (Tina)

Fay talked about how having her CRT-D had improved her cardiac function and ceased her frequent hospitalisations, which changed her relationship with her friends. She like the way the focus had shifting from her ill health and allowing her to blend in more equally, explaining,

It is nice not to be asked every day 'are you alright?' oh the odd person does say 'oh how are you today?', but it is good not to be the centre of attention but to be just normal. (Fay)

Friendship was another relationship valued by these women after they received their ICD. They appreciated the practical and emotional support friends provided as well as the sense of comradery. However, friends could not relate directly to the experience of living with an ICD, this specific support of peers was missed by some women and informally obtained by a few others.

Relationships with healthcare staff

While peer support was largely absent for these women, most were offered some degree of ongoing professional support. This varied over time and across the two tertiary hospitals, and was perceived and utilized differently by individual women. Lisa established a comfortable and positive relationship with support staff while at her tertiary hospital, and continued to freely seek contact and advice once home.

She was my nurse, she said if I had any doubts just to ring her so I did and she said no don't do that and don't do that... so a lot of it I liaised with her and I rung her up and we sorted through it. (Lisa)

However, as a retired healthcare worker, Beth had not sought continuing contact with healthcare staff after her primary prevention ICD, explaining,

I haven't had to contact anyone. [Tertiary hospital specialty clinical nurse in rhythm management] gives you a card and you are free to contact her at any time, but she must be a very busy person. If you think how many people have had these devices over the years I hope they don't all ring her! (Beth)

Rose strongly desired ongoing support both from peers with an ICD and healthcare professionals, but was unable to share her problems and express her emotional quagmire of increasing depression and alcohol dependency. She spoke of a nurse, saying,

She rung me a couple of times, but that was sort of only in the first month... most of us are not going to sit there on the phone and admit that I feel you know... (Rose)

Positive interactions with medical and hospital staff were strong sentiments spontaneously volunteered by most of the women interviewed. This positive interaction with staff was seen as helpful in navigating their experiences of receiving and living with an ICD. It was clear all women knew the names of their doctors and surgeons, the local electrophysiologists and some nursing and support staff. They often referred to health care staff by their Christian names and gave anecdotes encapsulating their relationship and what it meant to them. For example, Lisa said,

The nurse I had up there, she actually had [an ICD], she went through the whole thing and I think she had it in 5 years when I met her. She got saved by her husband and, uhmm, even though she was a nurse she had a cardiac arrest! Yeah, and I was like oh,

so that made me feel a little bit better, that talk to her, so her family was quite young too and that made me feel a hell of a lot better. (Lisa)

During her interview Vera also often spoke of people she had met on her journey to receiving and living with an ICD. Her anecdotes reflecting a deep appreciation for the individual relationships and care that was taken of her personally,

I will tell you about nursing..... I hadn't eaten for 3 days, a nurse [name removed] came in and she said 'can you shut your eyes, can you see any food when you shut your eyes', and I said 'yes I can see fresh pineapple'. Half an hour later she came back with 4 pieces of fresh pineapple on a wee plate and she said 'try one of these'. So I ate one and over an hour I got through 4 pieces, and when she came back, 'would you like some more?' I said, 'oh I am so impressed, fancy a hospital having fresh pineapple!' And she said, 'oh my husband works night shift so I woke him up and got him to go into New World in the city and get you a pineapple and we cut it up in the nurse's room'. Oh, and I thought, oh God, what sort of nurse. (Vera)

Clearly these women valued their personal connections to health care staff members and therefore also valued any continuity of care they received. This was especially apparent amongst the many women who had several admissions in local and tertiary hospital facilities and ongoing outpatient contact with cardiologists, electrophysiologists and their general practitioner,

Dr [name] a nice, lovely lovely man, he's been with me since day one, he had only just started in [hospital name], and he is just lovely, I think he is marvellous and has stuck with me. (Rose)

I had real good faith in that lady that does them, I trusted her, and when I went back to get the other one in and it was the same lady. (Enid)

Some women, like Lisa, even tracked the career progress of staff members they were involved with,

So she made me feel really good and it was good to hear that she actually got promoted to running it. (Lisa)

Within the regional district health board responsible for these women, provision of specialist services like electrophysiology testing and cardiac device implantation was contracted outside of the district to tertiary hospitals. Over the nine years that the longest serving ICD

participant had their device, the location of these services had changed. Initially implanting and routine follow up was provided from the same tertiary hospital (A), implantation then changed to another tertiary hospital (B). However, routine follow up and monitoring services continued unchanged (from hospital A), until a couple of years ago when a local hospital based electrophysiology clinic took over follow up management of cardiac devices, with implantation still occurring out of district in tertiary hospital (B).

Changing service providers like this can disrupt these established relationships, something that some women regretted. While appreciating the new relationships and localised service, Vera discussed the changing service providers,

I am heart broken, I loved the girls, most of the girls who came from [hospital A] were in the theatre when I was, so I saw their eyes and they were going, 'it is alright'. They were so reassuring they were like a little group of angels looking after me, and psychologically I had put so much faith and love into these women, and to be suddenly put here with [local electrophysiologists] and not having any history with them and them not having any history with me, whereas with the girls from [hospital A] there was such a history. I don't feel that I am being spoilt in the same manner that I was up there, but I will say how lovely and easy with it so close and it saving the hospital board so much money not putting the [hospital A] girls up in motels and things. (Vera)

Loss of a supportive healthcare relationship was also reported by Fay in an entirely different context following her implant with a CRT-D for recurrent arrhythmias marked by frequent hospital visits. She said,

Not been quite a year since it [CRT-D] has been turned on, but I haven't been back in for almost a year, because in the end I was coming in every week or fortnight to have the paddles put on me [for external cardioversion], I was starting to get scorch marks... It was my second family, I was always visiting, yeah I miss all my old friends at the hospital. (Fay)

Essentially these women established positive therapeutic relationships with staff providing their healthcare. These relationships were beneficial as they helped them to feel secure and comfortable with their medical care, enabled them to question and seek information as they needed. The continuation of these relationships was also valued.

Wider community interpersonal interaction

Women also recognised the energy that interpersonal relationships take from them as well as give. The potential drain on personal resources caused some women to limit their exposure to more distant connections. Mere found that “any human energy took my own energy”. She noticed that in public spaces like the supermarket and at Hui’s [meetings] there “can be toxic people... which is bad for my own energy”. She explained that she did not have the energy to handle their vibrancy particularly when she was feeling unwell. Mere had therefore altered her wider community interactions and relationships, choosing a role with reduced responsibilities at hui’s [meetings] and tangi’s [funerals] rather than organising them as, since her CRT-D, she had found these activities to be emotionally and physically draining. Rose also understood the burden of having responsibilities to the wider community. She was very keen on the concept of a support group for ICD recipients saying,

I think why don't I get a support group going for the younger people? But I don't know if I have actually got the energy to give it what I think it needs, 'cause I do get tired, I get very tired... because I've got enough on with me and my family, I don't know whether I want to take on other people's problems, I know that sounds really selfish. (Rose)

While Rose and Mere chose to avoid larger scale public interactions and wide interpersonal relationships, Ana maintains extensive community networks and relationships, attending and organising several hui’s and community groups. She felt,

As long as you think you can cope with being able to do it, why not? You will know in yourself when you can't cope with those things and it is time to step back and let others take over, because you can only do so much. A lot of the younger ones look to you for a bit of guidance anyway, but if you can be of a help to them make use of it 'cause you are not going to be able to do that all of the time. (Ana)

Close interpersonal relationships were identified as supportive and motivating for the women living with an ICD. These relationships affected how they were able to navigate and process their experiences, affecting their actions and their emotions. Many relationships were reported as becoming closer and more valued than before their ICD, particularly for the women with secondary prevention ICDs. However, for some women, more public interpersonal relationships were viewed as unnecessarily draining and avoided, whereas other viewed these as valued and manageable.

Contemplating mortality

An ICD is a device intended to prevent the sudden death of those who are at an increased risk of lethal cardiac arrhythmias, therefore it is relevant to explore the meaning of death in this context for ICD recipients. All of these women discussed mortality to some degree, some focused on thoughts and feelings towards death and others on life. Within this section various aspects of this contemplation will be covered. Differences are noted between the primary and secondary indication ICD recipients' meaning of 'if' when discussing death, such as the secondary prevention group's practical knowledge that death can be sudden and unpredictable. Comment about the potential benefits of a sudden death are also highlighted. Emotions and attitudes towards life and death will be explored. Subsections include, uncertainty, dwelling on death and depression, avoidance and fear, carrying on with life, acceptance, being thankful, re-prioritising and enjoying life. How the women practically planned for death will also be addressed.

The meaning of 'if' when talking about death...

An ICD is indicated for individuals who are medically assessed as most at risk of sudden death from cardiac arrhythmia. Therefore, as part of consenting to having an ICD implanted, these people are required to contemplate their personal mortality more closely than those who have not been specifically told that they have an increased risk of dying. The extent to which the women interviewed contemplated their eventual death, and the impact this contemplation had on them, varied greatly between the women with primary indications and those with secondary indications for their ICD. For example Beth, who had a primary prevention ICD, could still talk about death and cardiac arrest as an abstract possibility, stating when she talked about the decision to have an ICD,

I though some day it may be an advantage, if at some stage you do have a cardiac arrest and you do want to live a bit longer and you are not ready to go yet. (Beth)

However, for the women who received a secondary prevention ICD, death in the form of cardiac arrest was something they had already experienced and were therefore forced to see it in more immediate and realistic terms. Like Lisa, these women related stories that hinged on 'if', such as 'if one little thing had been different I would already be dead'. As Lisa said,

I would have been dead, if my neighbour hadn't made me go to the Doctor. (Lisa)

Realisation of the importance of this 'if only' situation in the continuation of their lives and the reality of their mortality had a big impact for these women, as Pam states,

I was shocked that I could be dead! If I hadn't had [partner] there to do CPR, if it had happened when I was in the bathroom not the kitchen, it could have been a different story because they wouldn't have found me straight away and I would have been passed away and yeah that brings a bit of a shock to me. (Pam)

As Pam articulated, the nature of surviving a cardiac arrest usually requires somebody to actively prevent death by providing resuscitation. These women recognised and valued this intervention and the actions of another. Tina said,

Without my neighbours, without those two neighbours, I would have been dead! Mum absolutely loves them, 'cause they stepped up and started working on me. (Tina)

Sometimes this gratitude and sense of indebtedness is for a stranger, with Nora saying,

My thing is, I've never even been able to find out where it was, it just says an alleyway, but somebody helped me and got an ambulance, and that person saved my life. (Nora)

Ultimately, the purpose of the ICD is to remove the dependence on the intervention of others to provide resuscitation in the event of a further cardiac arrest. Gail explained how the ICD can also be recognised as the 'if' factor that allows life to continue, when she said,

My device went off twice, both appropriate, and I was told in [Hospital name] that if I hadn't had it I probably wouldn't be here. (Gail)

The cardiac arrest survivors clearly recognising that the reason they were still alive post their cardiac arrest was because of a propitious collection of unpredictable variables. Jill summed it up as being,

Just so lucky or I wouldn't be here, very lucky. (Jill)

Death as suddenly nothing

The secondary prevention group understood their cardiac arrest as death or a near death experience, like Tina who emphasised her understanding of the situation as,

I died... you do realise that a cardiac arrest is that you actually died, that they bring you back to life! (Tina)

These women used their experience of cardiac arrest as a guide to how death would manifest itself again for them. Lisa said about death,

I actually experienced it! I was gone for a couple of minutes, yeah no it was a real reality, it just felt like sleep and I woke up to all of this. (Lisa)

Lisa implied that the problem was not with the death but of waking up to the aftermath, with the need to eventually continuing life with an ICD and the knowledge that she may have further potentially lethal arrhythmias. Like Lisa, most women could not recall their experience during their aborted sudden cardiac death. Nora also said,

I've got no memory of it at all, so it doesn't worry me. (Nora)

While this was reassuring for Nora, and for several other women, in the sense that they felt it was 'not so bad' they could 'do that again', having no recollection of the experience was disconcerting and disappointing for others, such as Ana, when she talked about her "near death experience",

It was a bit scary because you don't really know what's - You know - some people can actually give you an idea of what they saw or what they think went on, but my canvas is a bit blank. I never really saw anything at all, I can't recognise anything, I just know I can't remember. (Ana)

Vera was the only woman who reported a detailed awareness of this experience, which occurred during the first of her several cardiac arrests. She recalled,

I went flying up to the ceiling and I could see two nurses working on me down there and I'm up here sort of shaking around and then... I went crash back down on the bed and the nurse with the worst bad breath in the world was pumping me. (Vera)

Along with their knowledge that sudden cardiac arrest is a death in which there will be both nothingness and suddenness, several women who survived a cardiac arrest also referred, even if in passing or jest, to deeper concepts about death. Rose, for example, referred to the concept of heaven where deceased relatives were waiting to see them again,

It [arrest] was only three months after I had lost my dad and that was absolutely huge...he [Doctor] came in and said to me 'you are one very lucky girl', and 'I said yeah I've just lost my dad and I don't think they want me up there just yet!' (Rose)

Tina and her teenage children took to referring to her cardiac arrest as a form of rebirth, with Tina explaining,

My kids are funny, we give each other shit all the time, my youngest says I'm only three years old, 'cause of my cardiac arrest and I said 'I like you' (laughing)... so she says 'I don't have to listen to you, you're only three', and I say 'come over here I can still boot you!' No, they are really good. (Tina)

The benefit of a sudden death by cardiac arrest

While an ICD aims to prevent sudden death from cardiac arrhythmia, it does not prevent death from other causes. Death from an untreated cardiac arrhythmia can be, as the women with a secondary prevention ICD have already discovered, felt as 'suddenly nothing'. Compared with other descriptions of dying this method of dying may seem desirable, so the meaning and value attributed to death can become situational.

Vera was the only participant to note that her perception of death had changed with her personal health circumstances and how the benefit of a sudden death became apparent. Vera's awareness of this changed her attitude towards her ICD over time. Vera received her ICD when she was aged in her mid-70's after having arrhythmias since her 20's and living with the expectation a sudden cardiac arrest since then. She had her first cardiac arrest and MI at 40 years old, which reduced this threat a little but she never expected to grow old. She explained her feelings on first receiving her ICD,

When I first got it I thought it was the most wonderful thing in the world and I was proud of it and we went [overseas] for a holiday and things like that, and really started living again like a 73, 75 year old should live life. (Vera)

But, she continued, "now it is a different story, how I feel about my ICD". As time passed Vera aged and her physical health progressively deteriorated, something she never contemplated living long enough to experience. She said,

So now I am cross, 'cause my heart is a beautiful 70 beats per minute and it doesn't matter what happens it is just gorgeous, but my muscles are - I've got myopathy and my muscles are just dying. So my beautiful heart is under control a bit, it is wonderful but now that I am getting weaker and weaker I think, oh shivers, oh well maybe it would have been better if I hadn't had it, if I end up choking and being crippled, I haven't got

anywhere near that yet, but my view went from 100% wacko dance on the roof, to...
(Vera)

In this situation Vera felt that, compared with dying slowly of a painful and disabling condition, a sudden death through cardiac arrest is perhaps more attractive to her, but is now prevented by her ICD. Her concept of this was unique in this study and perhaps reflects that she was the oldest participant and had developed another disabling and life limiting health condition.

This awareness of the speed and suddenness with which death can occur influenced how these women coped with living with their ICD. This is particularly true for women with secondary prevention ICDs who had more closely contemplated death.

Emotions and attitudes

The women described a variety of emotional responses and attitudes towards mortality and their individual journeys with their ICDs. These responses could occur simultaneously and fluxed over time. However, the women reported a tendency to move from the more negative feelings to the more positive ones over the course of their journey. As Lisa stated,

A lot of it is how you process it. I found once I got to go back to my natural normal life, I was ok. (Lisa)

Uncertainty verses confidence in the ICD

While most women acknowledge that their ICD provided security and a form of insurance against another cardiac arrest, their degree of confidence in whether or not it could or would save their lives varied. Jill, for example, stated that she can only “*hope ICD kicks in if needed*”, and Lisa explained,

With this, [death] is a reality, it can happen just like that, even with the ICD, it might not work, you know, and it was a scary process to think of, but it is my reality now so it is part of my natural thinking. (Lisa)

Other women expressed a stronger belief in their ICD’s capabilities, like Gail who has experienced her device activate appropriately twice and said,

You know that if you have an episode you will be belted back in, so you have that security. (Gail)

Ana’s ICD has also appropriately activated and she too believed that it could and had prevented her death, explaining her view as,

Well it I think my ICD is a lifesaver really, I couldn't do without it, it is my soul mate, I don't think I would want to be without my ICD, I wouldn't be here anyway. (Ana)

Even women without an ICD activation were confident in its ability to save their lives.

I am actually very relieved that I have one there because I know that if something else was to happen it would automatically kick in and do its job. (Pam)

For most of the secondary prevention group, having an ICD, however, strongly they believed that it would work for them, allowed them to continue life without having to worry about being alone without an external resuscitator present. Even Jill, who only “hopes” her device will work, explained,

Yes, I have to live with it [ICD] but without I wouldn't be here, in a sense of, you know, that it is part of my life now and it might save my life next time, 'cause, as my boss said, you can't take [colleague who provided CPR] around with you everywhere and he has done it once and he is not doing it again! (Jill)

However, Rose initially used her confidence and belief in her ICD's lifesaving capacity to provide a sense of immortality, allowing her to rationalise other negative health behaviours. She revealed,

Emotionally I hit rock bottom and I just nosedived into depression and because of that I decided that my way out was alcohol and I decided that that was my cure all and I'm going to be fine because I've got this device and no matter what I do or how much I drink it will kick me back. (Rose)

Depression and dwelling on death

Three of the interviewed women spontaneously shared the information that they had been clinically treated for depression, all of whom had received secondary prevention ICDs. Jill struggled with negative thoughts and reoccurring anxiety around death. She said,

You do think about death... death is frightening because you don't want to miss out on people you leave behind, 'cause they keep on living and you have got to get off the boat but you don't want to get off the boat... I think I know what the 'cause was, in my mind all I kept thinking was I am going to die before I see the [overseas grandchildren] again. It was still in my mind that I was going to die and I couldn't get it out of my brain. (Jill)

Rose had briefly taken antidepressant medication prior to receiving her ICD. She said she had “*learned to cope with the mood*”. However, following her cardiac arrest which led to an ICD implant, physical weakness, the loss of both her job and her driver’s licence, she felt like,

Everything had been taken away, my whole life had just been turned around, [husband] worked night shift so he sleep during the day, I couldn’t do anything, I was stuck alone at home during the day by myself...It did take a wee while, but when I look back you can just gradually feel it go, go, go, each day it got a bit worse and each week was even worse. (Rose)

Jill and Rose both sought help from their general practitioner (GP), and utilized antidepressant medication to help them cope with this new phase in their lives. Jill reported identifying the need for help relatively early and how her GP opened the conversation with,

‘You seem different somehow’ and I said ‘to be honest I still can’t find me’, and I said ‘I can’t explain it any more than that. The only words I can find is I can’t find me, some of me I think is lost’, and she spoke to me and had a wee chat and she said ‘I think you need a little bit of help to get back on your feet and back to your bubbly self again’ and she gave me some pills [antidepressants] to take and I’ve been a hell of a lot better since I’ve been on those. (Jill)

However, it took Rose over a year to identify and address her mood issues, after having ‘self-medicated’ with alcohol. She reported,

I had a terrible time, I really did. I then went through a variety of things. I went through a treatment program for alcohol abuse and that is the best thing I ever did, [program name], it is based in town and that really got me not only to look at a lot of issues for me but also to react and interact with other people, ‘cause there was some people of my age group, that somebody to talk to, it is difficult to explain, but I needed to do it for me, and that was really good and then I got into some volunteer work and then into the workforce. (Rose)

Interacting with other people and, in particular, returning to the workforce, reduced the time she spent alone with her thoughts and the opportunity to dwell on negative aspects of her experience. Even women who did not report depression identified being busy as a useful technique in reducing the opportunity to dwell on death and ill health, with Ana noting,

I am probably more active now than I was 10 years ago, I think it helps me to forget that there is anything wrong, you know 'cause I haven't got time to think about anything else, I can only think about what I have to be doing today or what I am doing tomorrow.
(Ana)

This is not straight forward, however, as the presence of negative thoughts can inhibit the desire to seek out distracting activities as Jill recognised on reflection,

You do think about death, but I don't so much now, [feeling] stronger in myself, especially on these pills I don't think about it so much, I think that was part of the problem before. I would sit there and think about it and worry about it and you become quite antisocial because you are too worried about dying. It is very hard to put into words actually..... but I feel a lot better now. (Jill).

Gail also struggled with a low mood and morale initially. She had a cardiac arrest, ICD implanted and was twice shocked from her ICD all within two months. She found that with these cumulative experiences,

I had one day that I cried so I was very annoyed with [cardiologist] 'cause he insisted that I be seen by a psychiatrist who put me on some medication, which I was absolutely no good on, and knew damned well I didn't need! So as soon as I got out I went to my own GP and said, I know I was supposed to take a quarter and even so it was zonking me out, and he said...what was happening was a result of trauma, so we immediately got off that. So I felt it was just making a situation that was difficult more difficult. (Gail)

While Gail found the effects of antidepressant medication to be undesirable, at the advice of the tertiary hospital team after her device activations she requested counselling to help her process and cope with her experiences. She already had a good established relationship with a counsellor after previously working through some family issues so,

All that happened basically was that I had to explain to her about the device and from session to session I just simply told her what I had done, 'cause I had decided, being me, that I would do my own recovery, so that is what I did, step by step and it went through until the final one was the first day that I was able to drive. (Gail)

Gail found counselling to be very helpful in working through her reactive depression.

Avoidance and fear

Some women with secondary prevention ICDs avoided situations that they associated with their cardiac arrest, due to an underlying fear that this could reoccur. However, for Vera, her biggest fear was related to her CRT-D device itself. She was dependent on this to provide a heart rhythm and she was initially fearful about how she would die and how her death would be recognised, saying,

My biggest fear you know, is that I would die of a cerebral haemorrhage, and I would be lying there and the nurse would come along and say 'no she has got a perfectly good pulse 74 beats, nothing wrong with her really', and as I rot and suppurating pus drips off my finger another little nurse comes along and says 'no she is still alive', but that is not what happens, once you die it stops... but no I would love to know if other people were worried about it. (Vera)

Rose had her cardiac arrest at home in her kitchen just after having had a shower in which she had coloured her hair. Her fear was associated with that event, and she explained how she spent several years avoiding being in a similar situation. She explained,

It took me till, probably only about six months [ago], before I could put a colour in my hair again. I associate that with that collapse, it this thing that really hit me in the face and I thought oh this is going to take me a wee while to... My hair went white... Even now I avoid having a shower when I am here on my own, I don't you know, I would rather wait till someone is home. (Rose)

Nora said,

I must admit that I was a bit scared to walk into town on my own, thinking you know 'could this happen again?' (Nora)

However, Nora lived alone and walking was her primary means of transport. This was an activity that she needed to continue with and did, so this fear abated. Jill explained a more generalised fear for this group of women, which she found abated over time and as normal activities displaced this, as,

When you first get home you get very jumpy in case it happens again, so you are a bit hyper-aware, but as I say, I found it brilliant being able to go back to work. (Jill)

Carrying on

The women valued being able to carry on with their ordinary activities post an ICD implant. While Jill talked about her initial depression and preoccupation with death, she went on to say,

Got to move on with living. So it is just one of those things, now that it is over with is done, life ticks along beautifully, it is back to work tomorrow and a haircut this afternoon and it is good, normal life. (Jill)

Enid agreed with the importance of carrying on and staying busy, saying,

I've too much to do, places to go and things to do, not to handle it. Just do your own thing and get on with things. (Enid)

Adding that,

Well life is for living. Life is too short, that is what I tell people. (Enid)

Beth received a primary prevention ICD and was clear that illness and emotion could not be used as an excuse for not carrying on, stating,

I'm sorry but we have to accept some things that we can't do anything about, and do the best you can do and we have to try to do our work, 'cause if you are still alive you have got to do something, don't you? (Beth)

Acceptance, facing mortality

While Beth clearly saw the need to accept the things she could not change, several other of the women interviewed also believed that acceptance was necessary for coping with their experiences. For example, Vera was in the unusual position of having spent most of her life expecting to die suddenly after being told at 24 years old that she would be dead by 40. She accepted this prediction, explaining,

I was happy about that, I really had come to terms with it, when I was told about it I thought well there you are, that is that. (Vera)

Decades later this comfortable acceptance of her mortality confused her doctor when he was giving her bad news,

He said, you know you are on dicey ground? You understand that don't you? And I said I am good with that, I am good with accepting that. Apparently I am a really good patient

because I accept everything, I face everything, I don't lose confidence in myself, they always say lovely things about me all the doctors and the nurses, so you know there must be lots of people that get depressed or worried. (Vera)

Enid had also considered and accepted the prospect of her death and the role of her ICD keeping her alive, especially since her ICD had activated appropriately. She said,

I've faced it [death]. I've used it, so without it [my ICD], I wouldn't be here. (Enid)

Beth had a primary prevention device that had not activated. She is a retired health professional and feels this role also helped her to accept death,

It [death] didn't worry me, it didn't worry me, what will happen will happen. (Beth)

Similarly, Rose's working life as a healthcare professional affected how she thought about death and dying. She explained,

I have dealt with death a good part of my working life, you know, working with the elderly, and it didn't really make me think about it anymore or any less. In some ways it made me count my blessings that I was here to be with my kids and to see my granddaughter grow up. (Rose)

Counting your blessings and being thankful

Like Rose, several women with secondary prevention ICDs were prompted by their cardiac arrest to count their blessings at still being alive. Rose expanded on this theme, saying,

It just did make me feel very thankful about what I have got, and I still feel like that even now. So really, for me, it makes me very thankful for what I have got. Ok, events I've had made me reflect on what a great life I have had really, and I have been so, so, lucky to meet so many people, we have been married 40 years and so I'm very lucky. It really does, it has an impact on your life but as I say I am just really grateful for all I have got (Rose)

Mere also said that, "lots of things bring home how lucky I am" and Kate knows "not to take things for granted" in her life. Gail made a choice to retire after her community cardiac arrest and while this resulted in changed financial circumstances she still counts herself as lucky,

Just having this opportunity! Because you know that my life was so busy before with teaching and looking after [child], but now with this luxury of time! I would still like a lot

of money to fall down, but who doesn't? So I feel I have got life again pretty much how I want it. (Gail)

Enjoying life

Some women expressed the need to be happy in the present. Many listed the good things in their lives. For Lisa, her cardiac arrest meant that, afterwards, she wanted to enjoy the moment and seek out positive experiences. She explained how she did not want the fear of death to prevent her from doing things that she enjoyed,

If anything I want to do more, 'cause it [death] might happen, so I just go and do it... you got to think, I don't do it and it [death] happens anyway or I go out doing something I love, that is how I look at it. (Lisa)

Tina explained,

I don't care what anyone thinks, you know, I just live my life like it is my last day. I used to let things get to me, but now it is just, like, I don't care, I'm happy with how my life has gone. I'm lucky I have still got my mother, I'm lucky I've got the two best kids in the world, and really good friends who have been there for me, and not just for me but for my mum and my kids, they were there for them. (Tina)

Tina then concisely summed up several of the emotions and attitudes around life and death common to the women with secondary prevention ICDs. She repeated a reflective discussion she had with her mother about dying,

I said to Mum, I live life like it is my last day because you never know when it is going to happen, and it did happen and I was lucky enough to come out of it! So I just appreciate everything around me, I just love everything around me. No I don't care, as I said to Mum, if it is going to happen it is going to happen, there is nothing I can do to stop it, and it is the same for everybody, I said anything could happen to anybody and if you keep dwelling on it you are not living life. (Tina)

Re-prioritising

Moving through from depression and into the more positive attitudes of carrying on, counting their blessing and enjoying life, can result in the re-evaluation of priorities. Gail explained,

I think it has changed my priorities, I mean you just consciously, you know, most days I have a list of things I want to do, some are household and some aren't and if I don't do them it doesn't matter. (Gail)

Jill's cardiac arrest and ICD have also changed her priorities,

It has changed how I think about life, things that I thought were important before, I mean I have never been like a materialistic person but things I thought were important before don't mean anything to me, priorities have changed in a big way. (Jill)

Kate said,

I know don't take things for granted, but it has not changed what is important [family]. (Kate)

Planning for death

Planning for death shows a degree of acceptance and often involves the women considering what is important to them, who they are leaving behind and how they are going to leave them. This subsection will acknowledge the importance of land and the place of death to two Māori women, and the practical planning activities that women undertook. Consideration or absence of palliative care planning for this population is also discussed.

Locality

Returning to, or dying in your place of origin where your links are, was important for two Māori women particularly. For Mere, once she faced the extent of her illness and mortality, she chose to return to her home town from a distant region of New Zealand where she had been based for many years. She returned to be closer to her extended family, to reduce the stress of being alone and the inconvenience to her family in supporting her. She had organised the practicalities of her death, including arranging for her ashes to be scattered in a treasured local area.

Lisa continued to live in her local community with extended family connection, however, she realised the importance of this to her when she visited a family member overseas for a holiday, stating,

When I got over there I ended up getting really bad, like, pins and needles and I thought oh my god, that sort of made you paranoid... I was starting to get into a panic, 'cause 'I

don't want to die over here, I want to go home'...I just didn't want to die in Australia, so I had a couple of anxiety attacks over there. (Lisa)

While she realised she did not want to die overseas, she had otherwise accepted her mortality and had never experienced panic attacks before this incident while overseas.

Practically planning for death

Mere, who has a CRT-D for cardiomyopathy, experienced a recent decline in her physical health. This had prompted her to visit her children overseas to say her “*final goodbyes*”, as she felt that she would die. She had since had her device recalibrated and felt much stronger and said she thinks she “*can do many more years*”. However, she said,

I did my will, said goodbye to people, sorted my life out. (Mere)

Like Mere, other women were prompted to put their legal affairs in order. Rose was prompted by the realisation that in her household she was responsible for all the finances, insurance and legal paperwork and that when she died her husband would be unable to easily take over. She explained,

I don't think that [husband] here would cope, 'cause he would never get any banking done, he doesn't know any passwords or anything.....the one thing I did when I came home, I went and brought a filing cabinet and filed all our personal papers, and there is our life insurance and there is.. so a little of organisation. It made me organise some things a little better, 'cause I was the only one who knew where things were, so I did do that... I organised my personal stuff a little better. (Rose)

Gail also realised that things would still need to happen when she died which instigated her planning for the practicalities of death and the aftermath. She said,

Someone said we have to have a meeting, in case there is going to be a funeral, and I thought no way! It is going to be my funeral! So I have arranged my funeral, I have almost paid off my plot and I have appointed people so if it does happen everything is there, including the music, some of it which I am going to sing, I did that, I redid the will. (Gail)

Organising and planning her funeral service gave Gail a sense of control and input into the process. A sentiment common among those who planned for death was that it was not a

morbid thing to do and once it was done it could be put in the background. Gail expressed this as,

This is what I have done and it is not negative. (Gail)

Palliative care

Only two of the women interviewed raised the issue of palliative or end of life medical care and their expectations around this. Both these women had secondary indication devices, were at the older end of the age range and had other co-morbidities that either had been or were becoming physically limiting. Ana found out that she was classified as a palliative patient by her general practitioner incidentally, from the receptionist, when Ana enquired why the clinic had stopped asking for payment. She was confused by this, saying,

My GP classes me as palliative care! I don't really think I am palliative care, am I? (Ana)

For Ana, despite her co-morbidities, the concept of palliative care for herself was still startling. Especially as, although she had poor physical health initially after her secondary prevention ICD requiring frequent paid GP visits, she felt her health had greatly improved at the time she discovered that they now classified her as receiving palliative care. Ana indicated that she had not discussed this with her GP, partly because she did not want them to reconsider and ask her to pay for her doctor's visits again and partly because she felt that if this is the end of her life, she cannot change that anyway. She considered its meaning, however, saying,

Well in one way I think it is a good thing 'cause I don't have to pay and the other thing, I think, well, palliative care?! I think to myself well I wonder, what is around the corner, 'cause really palliative care is giving you a better standard of life, 'cause you are at the end of it. (Ana)

However, Vera had had the opportunity to discuss her wishes and expectations of end of life care with her GP and family,

My doctor has given us, like, a four page thing on what you want in the last stages of your life, and all my kids have got a copy and I think that is the most brilliant thing. (Vera)

Vera spent much of her life expecting death and said therefore it was discussed openly “*the whole family talks about death, the kids were prepared*”. She finds the different attitude of her neighbours in their 70's to be unpractical and obtuse, as,

They have never once discussed death or what they want with funerals and that and they are appalled that I have written out this four page questionnaire about what I want, and yet we think it is marvellous that the kids have got that while I am still alive to see what I would prefer, it doesn't mean I have to have it, but I found that very reassuring, I thought that was lovely. (Vera)

Ending it all

As part of her palliative care plan Vera stated she had the opportunity to turn her cardiac device off. Vera had a CRT-D device without an intrinsic heartbeat. The defibrillator component (or 'D') can be disabled in all devices and will only alter the course of an individual's life when or if s/he goes into a lethal cardiac arrhythmia. However, disabling the CRT component of a CRT-D means no heart beat is maintained and the patient dies instantly. Vera views this level of control over death as "wonderful insurance", saying,

If I get a brain tumour or I get something else and my life becomes miserable I can tell my doctor I don't want to keep going on... my doctor has to ring [devices remote monitoring hospital], and say that 'she has had it', and I have asked my family to come down and on five o'clock Friday, in the afternoon they will all be around my bed and [devices remote monitoring hospital] will turn me off... I thought it was convenient, my family could leave their jobs at lunchtime to be here at five o'clock on Friday and we could have a quick cremation and they could be back at work on Monday. (Vera)

Vera is clear about the situation and timing when she could use this option. She had also considered her husband in the timing,

As soon as he dies I can die, but I can't die purposely and leave him because that's a horrible thing to do. (Vera)

She added,

You don't want to be a helpless vegetable and just keep living because there is a machine in your heart. (Vera)

While Vera is personally comfortable with the role her ICD/CRT-D has played and can play in her life and death, after having had multiple cardiac arrests and fifteen appropriate shocks, she is aware that these attitudes are not shared by everyone, even within her family. As she explained,

In the mean time I've got a sister who is a Christian missionary, and she keeps on saying you must die! God keeps calling you but you keep putting it off and so she almost makes like it was wrong to keep it alive. (Vera)

Death is an important aspect of the women's experiences of living with a device intended to prevent sudden cardiac death. This was more evident for the women with a secondary prevention device who had therefore had a near death experience prior to receiving their ICD. Actively contemplating death involved a variety of emotions, revealed underlying attitudes and became life focused for most of the women. When considering death, many women thought about practical issues related to their funerals and organised their lives to make settling their legal affairs easier for family members, viewing this as a positive action of control. However, very few women discussed their expectations around death and dying in the future, with the secondary prevention recipients' underlying assumption being that death will be like their previous cardiac arrest.

Summary

These women's experiences of living with an ICD varied, depending on multiple factors such as the device indication and antecedent events, the living circumstance of the individual and their personal and relationship resources. Receiving an ICD had a wide-reaching impact on many aspects of these women's lives, physically, emotionally, socially and practically effecting household management, childcare, leisure activities and employment.

CHAPTER FIVE

Discussion

Introduction

The purpose of this research was to capture women's experiences of living with an ICD in New Zealand. The interviewed women's generosity in recounting their experiences has allowed for a broad and detailed picture to emerge. It is clear that while every woman's experience is unique to themselves, there are some common themes amongst their accounts. To recap, these themes include, the effect of antecedent events, physical device realities and practicalities, positive value placed on interpersonal relationships and contemplating mortality. Within each theme there is a substantial variety of experience. This variety is influenced by factors like, the indication for the ICD, underlying and subsequent physical health and health care experiences, the personal social network and situation of each woman and each woman's internal resources and underlying attitudes.

While the women's generosity has made visible a wealth of experience, the discussion will focus on only some of the aspects of these experiences, particularly those that have implications for nursing practice. It is acknowledged that, due to the volume of data collected, many issues arose which will not be discussed in-depth, due to the size of the project and the necessary limitations put on it. The research aimed to identify any issues, obstacles encountered and sources of strength the women utilized in living with an ICD. It is intended, that by limiting the focus the discussion in this way, the information highlighted is that which could be used by health care services to provide more appropriate and relevant support for this population. The areas that will be discussed in depth in this chapter are, the discharge experience, physical activity, the impact of a driving restriction, the impact on being a mother, depression, end of life care and finally nursing and peer support for ICD recipients.

The discharge experience

The transition home from hospital was an area that the women felt was not well managed. This area was particularly difficult for the women who had been in hospital for longer periods after a cardiac arrest. The nature of their antecedent events impacted negatively on their level of physical condition and feelings of physical and mental vulnerability. All these women's devices were inserted at one of two tertiary hospitals, not located in their local district, this contributed to some of the difficulties around their experiences of discharge. However, so did a lack of appreciation for the practical difficulties of maintaining the medical

recommended restrictions and coping with physical and mental deconditioning in their home environment. While these issues were more overt for those with secondary indication ICDs who were in hospital longer, they were experienced to varying degrees by most of the women.

The majority of women were discharged home from the tertiary hospital that implanted their ICD. Due to the distances involved, and according to the Ministry of Health New Zealand (2009) National Travel Assistance Policy, women returning from tertiary hospital 'A' were flown home on a hospital flight. However, when services changed to tertiary hospital 'B', women were required to use private or public transport to return home when discharged, a journey of around 300km. This journey between hospital and home was difficult for many women, both physically and mentally, particularly for those who were inpatients for long periods of time after a cardiac arrest. Many women struggled to make the journey alone on public transport, finding they required assistance from strangers to manage. These women described feeling overwhelmed, terrified, weak, sore, cold and very alone during this experience. They found the physical demands of taxis, buses, or airplanes, walking, navigating steps and handling their luggage (without lifting) to be physically and mentally exhausting. Women with secondary prevention devices found this most daunting as their discharge home was often the first time they were away from direct medical supervision since their cardiac arrest. Jill described this as,

To get put on a taxi stand and launched on your own is terrifying, absolutely terrifying!... Daunting on the brain, and I do think that you do go into a wee bit of shock and you are terrified that it is going to happen again and there is nobody there. (Jill)

While no literature was found on the effects of this type of long distance discharge process, it certainly made a very negative impression on the women who experienced it. It seems likely that it could result in physical setbacks through fatigue and discomfort and potentially psychological issues if these feelings persist.

The women who transited back from tertiary hospital 'A' focused more strongly on the positive emotions, such as being glad to get home, with the biggest concern being a short delay in an available plane, rather than the emotional turmoil and discomfort that the other women's journeys entailed. How they were initially discharged home also affects how they view the prospect of future travel. A cardiac device has a finite lifespan, requiring replacement periodically, which for these women would mean travelling to tertiary hospital 'B' to have it done, which some of those discharged from this hospital now dread.

Once they returned home many of the women in this study referred to problems managing their household responsibilities and difficulties adhering to medically recommended

physical restrictions when they did so. Returning home from hospital entails significant daily obligations, the physical implications of these are often underestimated. Gosse, Fischbach, and Gosse (2011) found after a myocardial infarction and a three week rehabilitation course, that the average level of cardiovascular effort during standard domestic tasks was comparable to that of a maximum exercise test. They felt that their population, very much like the population in this study, was not adequately prepared for a return to household activities and that this would particularly impact on women who are most involved in domestic activities. Overall women contribute more effort to household chores and childcare and less to the workplace than men do, with women's total workloads being greater and more diffusely distributed than those of men (Gjerdingen, McGovern, Bekker, Lundberg, & Willemsen, 2000).

Very few of the women in this study reported receiving hospital initiated assistance at home on discharge, to assist with heavier household chores. While nine of the women lived with another adult, who could and did support their return home by undertaking increased domestic tasks, most of these women still felt the impetus to quickly return to their usual domestic roles within the relationship. This may in part be because women receive less assistance with household tasks from informal caregivers and report less support from their spouse than men, following a cardiac event (Kristofferzon, Lofmark, & Carlsson, 2003). Possibly because, in coping with a cardiac event, women tend to minimize the impact of their health situation and avoid burdening their social contacts (Bjarnason-Wehrens, Grande, Loewel, Voller, & Mittag, 2007). The women's main underlying attitude was encapsulated by Beth when she said, "*you know somebody has to carry on*". This is congruent with Mackenzie (2014) who found that gendered identity tends to dominate, putting the needs of family and especially children above women's own health, even in women with significant health issues.

All of the women with secondary prevention ICDs reported reduced levels of physical condition following their arrest and ICD insertion, discussing generalized weakness, loss of stamina and fatigue. This loss of physical condition varied in severity and persistence for the women but is consistent with other studies on hospitalization. Acute hospitalization is associated with decreased physical function, with a large proportion of patients being discharged from post-acute care settings below their prehospitalization level of function (Falvey, Mangione, & Stevens-Lapsley, 2015). During an acute hospitalization patients have periods of prolonged bedrest, with Brown, Redden, Flood, and Allman (2009) finding eighty-three per cent of a patient's day was spent lying on bed and twelve per cent sitting in a chair. Despite an ability to walk independently, on average only forty three minutes of a day was spent standing or walking. Prolonged immobility is associated with rapidly declining muscle

strength, muscle mass and physical function (Falvey et al., 2015; Gill, Allore, Holford, & Guo, 2004). In hospital, immobility and length of stay are related to functional decline at discharge from hospital and after one month (Zisberg, Shadmi, Gur-Yaish, Tonkikh, & Sinoff, 2015). This decline in physical condition during an acute hospitalization is also associated with less successful discharges from hospital and increased readmissions (Hoyer et al., 2014). In this study the women who reported longer stays in hospital tended to describe being physically weaker and struggling more on discharge. While one woman's physical condition appeared to directly result in a longer hospitalization, most women with a secondary prevention ICD indicated they were discharged home as soon as the testing, planning, waiting for and finally insertion of the ICD was completed. Women with primary prevention ICDs were in the community for their testing, planning and waiting, being only briefly admitted to hospital for the insertion of their ICD, minimising the negative physical effects of hospitalization.

Concomitant cognitive issues for the secondary prevention ICD population would also have influenced their functional status and coping once discharged home. Three of the women in this study referred to issues around memory and cognition post their cardiac arrests. This study did not specifically screen for or discuss cognition, so the actual incidence is unknown. However, the method of recruiting participants would have resulted in a self-selection of women less likely to have significant issues with their memory or cognition and all participants were at least six months post their ICD insertion, meaning any acute effects may have resolved. It is probable that many of these women were affected by some degree of cognitive impairment at the time of their discharge home, because the brain is particularly vulnerable to circulatory arrest with hypoxic-ischemic brain injury. Those who do suffer a hypoxic brain injury as a result of a cardiac arrest are likely to have long term limitations in daily functioning, lower levels of participation in society and a lower quality of life when compared with the general population. This participation in society is related to quality of life and is highly valued by patients, their relatives and society (Middelkamp et al., 2007; Wachelder et al., 2009). There have been multiple studies which overall show around half of cardiac arrest survivors are affected by mild to moderate cognitive impairment at three and six months post arrest. Memory problems were the most common cognitive impairment, found in cardiac arrest survivors, followed by impairments in attention and executive functioning (Moulaert, Verbunt, van Heugten, & Wade, 2009).

While the secondary prevention ICD population is susceptible to cognitive impairment through hypoxic brain injury, cognitive function tends to decline substantially anyway following hospitalization in older adults, even when controlling for illness severity and prehospital

cognitive decline (R. Wilson et al., 2012). These potential cognitive impairments would have a significant impact on their functional status when discharged home. As attention and executive function are significant determinants of functional status performance in managing basic activities of daily living and more complex tasks like managing money and medications (Grigsby, Kaye, Baxter, Shetterly, & Hamman, 1998). Executive functions are also important in mediating the onset and progression of physical functional declines and are predictive of functional mobility (Carlson et al., 1999; Gothe et al., 2014). Essentially all of these women with ICDs, particularly those with secondary prevention devices, were at increased risk of significant physical and cognitive impairments impacting on their functional performance of essential activities of daily living on their discharge home from hospital, although few received formal support around this. These impairments had an impact on their initial experiences of living with an ICD.

More effective discharge planning, factoring in potential impairments and specific restrictions post an ICD, could have better supported the women's experience of the transition home. Effective discharge planning is associated with decreased readmission rates, shorter length of stay but also with increased satisfaction, indicating an improved experience (Goncalves-Bradley, Lannin, Clemson, Cameron, & Shepperd, 2016; Jacob & Poletick, 2008). Several women expressed their dissatisfaction with their discharge process. Ana and her carer, who reported the highest physical support requirements on discharge home, felt that her needs were not well assessed and addressed prior to discharge. Placing the burden on her family and caregiver to assess, acquire and trial equipment to support her physically, they would have valued a comprehensive assessment and evaluation of the home environment and Ana prior to her discharge. As experienced by Ana, disorganised and fragmented arrangements for support is a key contributor to unsatisfactory experiences around discharge for patients, family and caregivers (Piccenna, Lannin, Gruen, Pattuwage, & Bragge, 2016; Rodger, Neill, & Nugent, 2015). To a lesser extent other women felt that in-hospital assessments of their discharge needs and functional capacity did not capture well their actual experience and issues once home.

The effects of the driving restriction was significant and will be discussed in full later, however, this also contributed to initial difficulties once discharged from hospital. Being unable to drive reduced the women's capacity to independently travel for household goods, medical appointments, children's needs and their own social activities. The difficulties in accessing these things contributed to feelings of isolation and loneliness once the women returned home. Only a few women obtained discounted taxi fares, but access to these was discovered incidentally. Gail felt everyone would benefit from this resource as soon as they were home. She would have

appreciated this being discussed or arranged as part of the discharge process, as it would have greatly eased her initial experiences and costs of running a household and parenting on her own without transport. The limitations and frustrations resulting from the driving restriction were a factor in many negative experiences on discharge home. Women tended to underestimate the impact and issues around the driving restriction until they were experiencing them, therefore this was not identified as an issue prior to discharge and therefore was less well planned for.

Ongoing support of a specialist nurse was felt to be important in enhancing quality of life by ICD recipients and generally those who received more support experienced the best psychological outcomes (Carlsson, Olsson, & Hertervig, 2002; Riegel, 1993). Psychosocial support and practical advice post an ICD was provided by specialist nurses based at the tertiary hospitals. This varied over time and across the two tertiary hospitals, and was perceived and utilized differently by the women. While this was helpful for some it did not appear to meet the needs of all women, who felt inhibited by the distance, perceived staff workload and method of communication with these services on discharge. The degree and nature of the specialist support that they felt able to access affected their initial experiences of discharge home, and how comfortable and confident they felt following medical restrictions and returning to activity. While specialist nurses' impact on the discharge experience post an ICD implant, they also impact on many other facets of ICD recipients experiences, so, this nursing role will be explored in full as a final discussion point.

A significant novel issue raised in this study was the negative effect of travel to a tertiary hospital on their experience, both in terms of removal from and/or significant disruption to usual support networks and in the transition to home. There appears to be potential to improve women's initial experiences of living with an ICD around their transition from hospital to home. It could be beneficial to pay more attention to the long and short term effect of independent long distance public transport on this weakened and vulnerable population. Better formal recognition and assessment of physical and cognitive impairments, especially in the secondary prevention population, would be helpful. Even a mild impairment can have a significant impact at home, so providing appropriate practical tools and services could reduce this impact and positively influence the transition home. Women found it difficult to realise the consequences of a driving restriction until they were home, so early planning on how they will manage this before discharge was identified as desirable. Access to specialist knowledge and support can also help women transition to living with an ICD.

Physical activity

Reduced levels of physical condition, particularly in those with a secondary prevention ICDs has already been identified and previously discussed. The following discussion will focus on what are the guidelines on physical activity for ICD recipients, how did they manage exercise, and what factors affect exercise, including avoidance, uncertainty and medical ambiguity. Medical concerns about exercise risks and actual benefits of exercise in the ICD population are also discussed.

Benefits of physical activity

The beneficial effects, both physiological and psychological of physical activity are widely recognised. There is strong evidence to support the benefit of exercise in reducing rates of cardiovascular disease, stroke, diabetes, metabolic syndrome, cancers of the colon and breast and osteoporotic fractures. Physically active adults have lower all-cause mortality rates when compared with less active adults (American College of Sports Medicine, 2013; World Health Organization, 2010). In randomized clinical trials of physical-activity interventions, the active participants show better health outcomes, including better general and health-related quality of life, better functional capacity and more positive mood states (Penedo & Dahn, 2005). In addition to the physical benefits of exercise, for some individuals like Lisa, their identity, social and family networks are heavily invested in their participation in organised sport, so continuing participation can help to maintain a sense of purpose, self-worth and belonging. Belonging to a sporting group contributes to improved quality of life and mental health through comradery, social support and validation within the team setting. Mynard, Howie, and Collister (2009) conducted an ethnographic study of an Australian rugby league team and identified that belonging to the team enabled participation in a personally meaningful and culturally valued occupation, which is certainly how Lisa felt about her sports team.

Guidelines on participation in physical activity

For healthy adults, at least 150 minutes of moderate intensity physical activity through the week is recommended by World Health Organization (2010) due to its significant positive impact on health and well-being. However, individuals with disease limitations should be as physically active as their abilities and conditions allow, as they will still have health benefits from activity, although some individuals may need to seek medical advice before aiming for higher levels of exercise (World Health Organization, 2010).

Medical advice is often based on the Bethesda Guidelines or European Society of Cardiology Guidelines, both from 2005, which give very restrictive recommendations on sporting participation for ICD recipients, only recommending activities like golf and bowling. These guidelines postulate that sports could increase the risk of ventricular arrhythmias, and potentially altered physiological states during exercise could result in failure to effectively shock arrhythmias, resulting in death. There was also concern about potential physical damage to the device and lead systems and that personal harm could occur in some high risk sports like skiing if there was a momentary loss of consciousness. However, these guidelines were based on expert consensus rather than researched data (Lampert & Cannom, 2008).

Regardless of the official guidelines, several studies have reported ICD recipients participating in a variety of physical activities not recommended by these restrictive guidelines, including vigorous and competitive sports (Kobza, Duru, & Erne, 2008; Lampert, Cannom, & Olshansky, 2006; Lampert et al., 2013). This is consistent with the women in this study, as many continued with some level of physical exercise. A few women participated in organised activities post their ICD, these included, 'kiwi seniors', badminton, line dancing and Lisa continued to play contact sports. Other women pursued informal exercise, independently walking and biking for fitness and transport. Several women had contemplated low impact water based activities, like swimming or aqua aerobics, but identified difficulties accessing these facilities as being a barrier to their participation.

Medical advice on safe activity levels was specifically sought by some women in this study, with varying recommendations. Conflicting medical advice from her GP and her cardiologist had caused confusion for Ana who ultimately chose to follow the more conservative recommendations of her GP. This problem arose as recommendations around sports participation for ICD recipients vary widely between physicians (Heidbuchel & Carré, 2014; Lampert et al., 2006). As the ICD population is expanding and becoming more diverse, ranging from teenagers with primary prevention ICDs for genetic rhythm abnormalities to older adults with secondary prevention ICDs with severe underlying coronary heart disease or heart failure, physicians' advice for individual's levels of physical activity may become increasingly variable (Heidbuchel & Carré, 2014).

Uncertainty occurs with ambiguity, when information is unclear. As Ana said "*who do you listen to, the specialist or the doctor?*" Uncertainty in the ICD population has been shown to be high at the time of initial ICD insertion and residing over time, reflecting increasing knowledge and an adaption to living with an ICD (Mauro, 2010). However, with situations like Ana's, uncertainty around exercise remained an issue, which is a potential problem as

uncertainty is associated with poorer levels of psycho-social adjustment and more psychological distress (S. Carroll, McGillion, & Arthur, 2014; Flemme, Hallberg, Johansson, & Stromberg, 2011; Mauro, 2008).

Reduction or avoidance of activity

The women in this study described themselves as lacking physical condition after their hospitalisation and ICD. For some, like Pam and Fay, achieving an improved level of fitness was a quick and easy process, but for others, particularly Ana, it was slow and arduous. Physical recovery was generally faster for the women who had a primary prevention ICD or those who described a shorter hospitalisation. Women who received a primary prevention CRT-D noted an increase in their physical capacity and were able to extend themselves beyond their previous level of physical activity. After her CRT-D, Mere was no longer short of breath when showering and was able to take longer walks in the bush and Fay was able to increase her daily walks and walk continuously without stopping to rest every few meters. However, outside of this group of primary prevention CRT-D recipients, no other women described increasing her physical activity above her pre-ICD baseline.

Many women in this study recognised the importance of staying active and maintained some level of physical activity but they often avoided high levels of exertion, commenting about reading their body, pacing themselves and stopping when they began to feel their heart rate increase. Pam said,

I know that what I am doing at the moment is fine. I am not making my heart race. It [ICD] might send alarm signals if I was doing some really physical exercise...going hard out. (Pam)

This attitude is not unique, with Morken et al. (2010) identifying that the majority of their participants with ICDs had also reduced their physical activity because they identified a rapid heartbeat and the symptoms of exertion with defibrillation. Like this study, most, but not all, of their participants regained a moderate level of activity. Physical activity remained lower than their baseline and they expressed uncertainty over what were acceptable levels of activity. McDonough (2007) also found half the young adults living with an ICD they interviewed described having to accept restrictions in order to live with their ICD, which included reducing their activity levels or avoiding certain activities. Like the participants in this study and Morken et al. (2010) some reduced their activity on medical advice but others chose to decrease their activity in response to normal exertional bodily cues, like a racing heart or shortness of breath.

In addition to uncertainty about what is acceptable, decision making about exercise is affected by an individual's personal beliefs about their ICD, beliefs which may not necessarily be true (Linder et al., 2013). In this study Jill limited her activity initially as she erroneously believed that walking was directly comparable to driving which was restricted. Kate also expressed concerns about her device being knocked during physical activity so, while she was comfortable biking and walking, she avoided athletics and activities around children that could involve physical contact with her device, a concern that was unduly limiting. Cutitta et al. (2014) also found many ICD recipients experienced behavioural limitations on their activity. While some reported simply being unable to engage in some physical activities, many also reported being able to undertake these activities but chose not to. Avoidance of activity was attributed to a perceived inability and a preference to avoid exertive activities and in some instances medical opinion. Lemon, Edelman, and Kirkness (2004) also found 55% of ICD recipients they surveyed reported avoidance behaviour, predominantly of activities. Others suggested that consistent and personalised medical advice could be beneficial in improving activity and confidence in undertaking and increasing levels of physical activity for those with ICDs, as well as psycho-social interventions to correct false beliefs about exercise (Humphreys, Lowe, Rance, & Bennett, 2016).

Avoidance behaviour is often linked to shock anxiety or fear of provoking an arrhythmia and ICD discharge. Tina feared not being able to drive again as a consequence of receiving a shock, and was therefore reluctant to engage in activities that she perceived would increase the risk of triggering a shock. This rationalised behaviour was also noted by Morken et al. (2010) and McDonough (2007) who found more than two-thirds of their participants described being cautious and aware of their health, surroundings and activities constantly in their daily life, aiming particularly to prevent the ICD firing and retain driving privileges. Avoidance behaviours can lead to both reduced quality of life and cardiac fitness (Humphreys et al., 2016). Lemon et al. (2004) did not find a relationship between the reported experience of shocks and avoidance behaviors, but the experience of an ICD shock has been found to have a detrimental effect on mental health. Kamphuis et al. (2003) found increased levels of anxiety in the ICD recipients who had received a shock, and Eckert and Jones (2002) also found feelings of anxiety and powerlessness associated with ICD shocks. Linder et al. (2013) found poorer mental health outcomes to be related to restrictions in ICD recipients' ability to participate in previous activities, with restrictions on regular exercise routines specifically, being emotionally difficult for many ICD recipients.

Concerns around arrhythmias, device damage as related to exercise

Despite these beliefs, those like Lisa, with long QT syndrome who continued to engage in sports, both with and without ICDs, had a low rate of shocks and cardiac events (Johnson & Ackerman, 2013). However, as Morken et al. (2010) noted, an ICD shock reduced physical activity at least temporarily. Lampert et al. (2013) also found that following an ICD shock 30% of athletes then ceased all or some of their sports involvement. The majority of ICD shocks, both appropriate and inappropriate, occurred during exercise and seven out of eight ventricular arrhythmia storms occurred during activity in the international registry of athletes with an ICD, although the efficacy of the shocks was good and there were no deaths or resuscitated arrests during exercise (Heidbuchel & Carré, 2014). Interestingly it has also shown that, while physical activity resulted in an increased number of shocks as compared to rest, there was no significant difference between intensive and otherwise levels of activity (Pavlu, Hutyra, & Taborsky, 2015). In controlled trials with non-athletic ICD recipients no significant increase in shocks occurred with an exercise program (Davids, McPherson, Earley, Batsford, & Lampert, 2005; Dougherty, Glenny, Burr, Flo, & Kudenchuk, 2015), with the researchers suggesting that the Bethesda and European Society of Cardiology recommendations to avoid sport in this population may be excessive (Johnson & Ackerman, 2012). It is considered prejudicial to prevent sports participation without considering individual factors, needs and benefits, especially if this prevents participation in recreational or professional sport where the individual's risk of lethal arrhythmia is low (Lampert & Cannom, 2008; Liz Almeida, Providencia, & Goncalves, 2015).

Exercise can exacerbate ventricular arrhythmias in cardiac conditions like hypertrophic cardiomyopathy, ischemic heart disease and long QT syndrome. There is also a concern that high levels of exercise in some conditions may result in adverse cardiac remodelling and promote an arrhythmogenic substrate. Exercise increased the risk of sudden cardiac death in the Physician's Health Study and the incidence of sudden cardiac death (SCD) amongst young athletes is estimated to be 2.5 times higher than in non-athletes due to underlying inherited cardiac disease (Heidbuchel & Carré, 2014). However, low to moderate levels of physical activity are indicated and encouraged for most people with underlying cardiac conditions.

Lisa was the only women in this study playing sport involving body contact. She padded her ICD site before playing and felt her experience gave her good skills in protecting herself and her ICD site saying, "*I can take a hit and I can give one too!*" Despite this, Lisa was also one of the women to experience device issues, a faulty line that required replacement, however, this had not been linked to her physical activity and she continued to play contact sports. Lampert et al. (2013) found that device and lead damage was uncommon, though most commonly

occurred through repetitive movements, such as associated with golf, even though current guidelines continue to recommend golf and not recommend contact sports. The researchers noted that ICD lead damage might be more common in those playing sports involving more aggressive body contact, but that their sub-population sample of those playing contact sport was too small to reveal this.

Limited by underlying condition

Functional capacity to exercise may be limited by underlying cardiac disease or other co-morbidities. Four of the women in this study had non-cardiac co-morbidities affecting their physical activity. Ana, Tina and Beth all had inflammatory joint conditions which limited their capacity for physical activity and altered which activities they opted to participate in and Vera was limited by her progressive myopathy. Other women like Rose and Mere had reduced cardiac function from previous myocardial infarction or cardiomyopathy which also reduced their exercise capacity. Despite this, the World Health Organization (2010) states that with pre-existing functional limitations, there is fairly consistent evidence that regular physical activity is safe, has a beneficial effect on functional ability and falls prevention.

Benefits of exercise with an ICD

Overall, the benefits of being physically active with an ICD outweighs the harms. The inherent risk of adverse events can be significantly reduced by a progressive increase in the activity level. While inactive adults will benefit from any increase in activity, the risk of sudden cardiac death and myocardial infarction is much higher with unaccustomed, infrequent vigorous exercise (Heidbuchel & Carré, 2014). Physiological improvements with a prescribed home exercise program are possible for ICD recipients, not just for the general population, with significant increases possible in their peak oxygen consumption and improved cardiovascular performance without the activity causing shocks or hospitalisations (Dougherty et al., 2015). This is consistent with the finding of Davids et al. (2005), who found that recipients who attended the outpatient cardiac rehabilitation exercised with a median intensity of 5.3 as opposed to 3.5 metabolic equivalents. Despite an increased exercise intensity the participants attending cardiac rehabilitation were less likely to receive any shock or shocks during exercise. Participating in an ICD-specific rehabilitation programme helped patients gain insight and develop a physical awareness whereby they continued healthy activities through interpreting body signals and adjusting exercise behaviour (Berg et al., 2012). Berg et al. (2015) also found that a comprehensive cardiac rehabilitation which combined exercise training and a psycho-educational intervention improved VO₂-uptake, general health and mental health, without a

significant difference in the number of ICD shocks or anti-tachycardia pacing therapy, despite increased exercise.

No specialised ICD rehabilitation programs were available to the women in this study, although an out-patient cardiac rehabilitation program targeting ischemic heart disease (IHD) was available locally for most of them. Attendance could have been difficult, however, due to the extended restricted driving period for the ICD recipients. Rose had attended this cardiac rehabilitation course after her first myocardial infarction several years before receiving her ICD, finding it useful in that context, but found the content inappropriate and repetitive post her cardiac arrest and ICD. Gail also attended a local cardiac rehabilitation program post her myocardial infarction and subsequent cardiac arrest and ICD. She said of this experience,

I didn't find that very good at all, there was no one there who had had an ICD... I couldn't do a lot of the stuff... it was just ridiculous the way you were being pushed.
(Gail)

So while a cardiac rehabilitation service is available to these ICD recipients it may not meet all their specific needs. Components of the cardiac rehabilitation program, like healthy living education, was applicable to both the ICD and IHD population and indeed, for some women, IHD is the underlying reason for their ICD. The opportunity to recommence exercise in a supported environment may also be useful for some. However, those with secondary prevention ICDs like Gail, will have experienced greater physical deconditioning than most other IHD patients on the course, potentially resulting in disheartening and frustrating comparisons with these participants. Gail also noted that attendance at the course she attended was male dominated contributing to her feelings of not belonging. A specialist ICD rehabilitation course in this locality would be impractical given the small volume of new ICDs being implanted currently, however, perhaps more targeted support and information for ICD recipients attending the available program would be useful.

Many of the women in this study found it difficult to return to doing levels of physical exertion that they felt comfortable with. Targeted and individualised support and education around physical activity, and how to manage this with an ICD, could improve this situation and help address the avoidance of activity by recipients. This could be achieved through a consistent message communicated to the ICD recipients through their wider healthcare team and supporters within a rehabilitation setting. The advice and recommendations regarding restrictions could also be reviewed. This will help improve the physical and mental health of ICD recipients.

The impact of driving restrictions

The difficulties and frustrations of having driving restrictions placed on them following an ICD implant was a strong theme throughout the narratives of the women in this study and had a significant multifaceted impact on their experiences. Twelve of the 14 women in this study held drivers' licences and regularly drove until restricted by their ICD placement. Here the history and rationale behind the legal driving restriction in New Zealand will be discussed, as these restrictions are not well supported by research. They also have a significant impact on the people they affect, as not being able to drive limited the women's independence in managing important aspects of their lives, including household shopping, medical appointments, social activities and attending to children's needs. The negative emotional and social consequences of these limitations, specifically isolation, depression and loss of autonomy and independence, will be discussed. How these women coped with driving restrictions and adherence to them will be explored with reference to other studies.

New Zealand's driver licencing system is controlled by the Transport authority (NZTA) which aims to ensure drivers are fit and competent to drive in order to minimise road traffic accidents and casualties. A variety of medical conditions, including cardiac arrhythmias, have the potential to affect the ability to drive safely, posing a risk to other road users as well as the drivers. Medical practitioners have a legal and ethical obligation to ensure the safety of all road users by following the NZTA guidelines in recommending when driving should cease (New Zealand Transport Agency, 2009). The rationale underlying these guidelines is based on the possibility that an arrhythmia may cause altered consciousness and a shock from the ICD with the potential risk of causing harm. The Canadian Cardiovascular Society originally calculated this risk of harm in 1992 by looking at four factors; time spent driving, the type of vehicle, the yearly risk of an arrhythmia and the probability that this will cause a significant accident (Canadian Cardiovascular Society Consensus Conference, 2003). The society acknowledged that risk is arbitrarily assigned and based on expert opinion rather than evidence based. However, using these factors they recommended a six month restricted period on a private driving licence following an secondary prevention ICD and/or and ICD shock, with two weeks as the minimum period of driving cessation for a primary prevention ICD. New Zealand still follows these recommendations (Canadian Cardiovascular Society Consensus Conference, 2003; New Zealand Transport Agency, 2009). However, expert opinions change and the duration of driving restrictions vary internationally. For example, the current recommendations on driving restrictions from the European Heart Rhythm Association are half that of the New Zealand

guidelines (Canadian Cardiovascular Society Consensus Conference, 2003; Norekval & Vijgen, 2010).

Jill and several of the other women in this study felt that the six month driving restriction was “*just too long*”, given the negative impact it had on their lives, and there is certainly evidence to support this statement. Early studies by Curtis et al. (1995) and Trappe, Wenzlaff, and Grellman (1998) examined driving and accident rates among ICD patients, both finding their accident rate to be lower than the general population. Curtis et al. (1995) found the fatality and injury rate for ICD recipients to be significantly lower than that of the general USA population, with an estimated fatality rate at 7.5 rather than 18.4 per 100,000 patient years and the injury rate from ICD related accidents to be estimated at 17.6 rather than the 2,224 per 100,000 patient years for the general population. Trappe et al. (1998) showed that ICD therapy and consequent motor vehicle accidents occur only rarely. These findings suggested that the rate of motor vehicle accidents from an ICD shock is low, with both these researchers concluding that excessive restriction and a total ban on driving appeared to be unwarranted. The Anti-arrhythmics versus Implantable Defibrillator (AVID) trial, supported these findings on reduced accident rates in the ICD population. It also found the data did not support even a temporary restriction in driving after a potentially lethal episode of VT, as there was no relationship between the duration of driving abstinence after an episode of VT and subsequent risk of motor vehicle accidents (Akiyama, Powell, Mitchell, Ehlert, & Baessler, 2001).

These three studies all used data from the 1980-1990s when ICD technology was new, (the first ICD was implanted in 1980). During this period ICDs were larger, placed with more invasive open heart surgery, and device technology and rhythm discrimination was more primitive resulting in more frequent shocks, both appropriate and inappropriate, than with current devices (van Welsenes et al., 2011). Earlier studies are also likely to reflect a slightly different ICD population, as ICD indications have widened since clinical trials have shown benefit in more diverse population groups, and primary prevention now drives the increased implantation rates. Thus, these studies were done on devices that were uncommon, had less refined rhythm analysis and therapy, during a time when ICD recipients were generally older, usually with secondary prevention indications (Curnis et al., 2008). Despite this, the studies could not support excessive or even temporary driving restrictions.

More recent studies, such as the Triggers of Ventricular Arrhythmia (TOVA) study by Albert et al. (2007), found that episodes of VF/VT did not increase while driving. The risk of ICD shock was estimated to be one episode per 25,116 hours spent driving. With the earlier studies by Curtis et al. (1995) and Trappe et al. (1998) both finding that only a small percentage of ICD

shocks while driving result in an accident, this provides reassurance that the risk of public or personal injury from an ICD related event is low. These findings were later supported by Curnis et al. (2008) finding an annual accident rate of 1.1% per patient years and only 0.1% where the driver was responsible. Thus, recent data still shows ICD shocks to be uncommon when driving a private vehicle and that motor vehicle accidents are infrequent in the ICD population and certainly not more frequent than in the general population. These researchers also suggest that the USA and Canadian guidelines need to be updated and specific restrictions on ICD patients driving cars need to be revised to reflect the current data (Albert et al., 2007; Curnis et al., 2008). Revised guidelines that reduced restrictions on driving would have had a positive impact on the lives of the women in this study.

Medical fitness guidelines on driving may also be seen as inequitable, as those with medical conditions appear to be held to a higher standard than the general population (Canadian Cardiovascular Society Consensus Conference, 2003). This concept is supported by the above studies which all found a lower motor vehicle accident rates amongst the ICD population than the general population, while the ICD population remains penalised with driving restrictions.

The driving restriction guidelines and related research all focus on continuing to drive and the perception of potential harm, particularly to the public, but do not consider the potential harm to the individual of ceasing to drive. The women in this research consistently described how driving restrictions made their lives harder, by draining their physical, financial, and family resources. When not driving these women found it more difficult to manage the usual tasks they undertook in their household and work roles, limiting their options to engage in everyday activities, work and social engagements. This caused frustration and contributed to loneliness and low moods.

While their driving restriction was only temporary, the issues the women in this study expressed have been identified in other populations where driving ceases. Low mood and depressive symptoms were reported by some women in this study, which they attributed at least partly to the consequences of not be able to drive. A meta-analysis of data from five studies by Chihuri et al. (2016) found the risk of depressive symptoms to be almost doubled for those who ceased driving. When studying Australian older adults, Windsor, Anstey, Butterworth, Luszcz, and Andrews (2007) agreed that driving cessation is associated with an increase in depressive symptoms. They also found that a decreased sense of control accompanied the increase in depressive symptoms when ceasing to drive, with drivers maintaining a stronger belief in their control of their lives.

This may be because ceasing to drive is considered by many to be indicative of giving up their independence and a major lifestyle restriction (Buys, Snow, van Megen, & Miller, 2012; Rudman, Friedland, Chipman, & Sciortino, 2006). Loss of control and feelings of increased dependence on others were expressed by many of the women in this study, associated with their driving restriction. This is consistent with the studies by Johansson and Stromberg (2010) and Eckert and Jones (2002) on ICD recipients' experiences of driving restrictions. Ragland, Satariano, and MacLeod (2005) suggested, however, that women were less emotionally attached to driving and the feeling of control associated with it, after finding that women had lower levels of depression than men when they stopped driving.

Differences in gendered driving behaviour and attachment to the act of driving was also noted in a Melbourne study by Unsworth, Wells, Browning, Thomas, and Kendig (2007). They found that while relatively few participants chose to relinquish driving entirely, women were three times more likely than men to modify their driving behaviour, even when health and disability were taken into account. Modified driving behaviour involved personally imposed restrictions, like only driving locally or in the daytime, rather than those legally imposed or medically recommended. Modified driving behaviours by ICD recipients, due to personal concerns of arrhythmias and/or shocks while driving, is not uncommon (Johansson & Stromberg, 2010). Some families of ICD recipients also imposed extra restrictions on them around driving, which could lead to tension within these relationships (Albarran & Tagney, 2001). Personally modified restrictions were referred to by several women in this study in addition to formal driving restrictions, but none reported familial restrictions. For example, Ana and Enid indicated that they self-restricted their driving to the local area and Vera chose mainly not to drive but would under certain circumstances. Given that women are more likely to self-modify their driving behaviour, many women in this study felt that life would have been much more pleasant and easier if they were legally allowed a limited driving radius initially after their implant, instead of a total restriction, enabling them to do activities like walk on the beach with their dog and get their groceries, have a haircut and visit friends.

This loss of independence and lifestyle restrictions arising from the driving restrictions negatively affected the lives of these ICD recipients. In Albarran and Tagney's (2001) qualitative study, ICD recipients and their partners stated that the most difficult part of having an ICD implant was the driving restriction as it was seen to have immediate lifestyle consequences, causing increased dependence on others, anger, resentment and reduced confidence. This sentiment was also expressed by the women in this study to varying degrees.

Public transport was generally not seen as an attractive transportation option by the women in this study. They expressed a variety of barriers to utilising public transport including limited access due to impaired health and mobility and being unable to carry heavy loads. Public transport was also perceived as expensive, less convenient and affected by weather, routes and timing. This is consistent with the findings of Buys et al. (2012) who found that for the majority of suburban trips a car is considered more convenient, regardless of the availability of public transport. The women in this study also found taxis to involve frustrating waiting and expense, although they were often used for household shopping. Subsidised taxi vouchers were accessed by only a few of the women.

Social isolation can increase once driving ceases (Buys et al., 2012). Bryanton, Weeks, and Lees (2010) also found that women experienced reduced social activities when they did not drive. This supports the findings in this study where women discussed the difficulties of getting out of their homes and maintaining some social relationships and activities with a driving restriction. Rose described the period of her driving restriction post ICD as “*a lonely lonely time*”. Women often discussed being unable to easily access their preferred leisure activities, usually waiting until towards the end of their restriction time before resuming them. These women enjoyed the interaction, social contact and sense of normality once they could commence these activities. Higher levels of social connectedness and community support are protective of psychological distress such as depression as shown in several Australian studies (Cruwys et al., 2014; Inder, Lewin, & Kelly, 2012). A study by Cruwys et al. (2013) found that, for those with depression or at risk of depression, belonging to a social group is both protective and curative. Those with depression who joined one group reduced their relapse risk by 24% and those who joined three groups reduced their risk by 63%. This supports the argument that there are benefits to recommencing social and leisure activities soon after receiving an ICD.

Planning for driving cessation can have a positive influence on the resumption and maintenance of social activities (Bryanton et al., 2010). This is not possible for secondary prevention ICD recipients, for whom the procedure is abrupt and unexpected. If primary prevention recipients are adequately informed about upcoming driving restrictions, however, they may be able to plan for their shorter period off driving. This could make their situation much less problematic. This was unfortunately not the case for Beth, who was not aware of the restriction until after her ICD was implanted.

The research would suggest that driving cessation alone increases women’s risk of depression post an ICD, particularly a secondary prevention device with its longer restricted time and the inability to pre plan for the restriction. The driving ban also makes it harder to

engage in healthy social activities that may be protective of depression. Certainly the women in this study valued the time during which when they were able to re-engage with their communities, at paid or voluntary work, or doing leisure activities. For many women this tended to occur only after or around when they were able to drive again.

In addition to the psychological and societal impact of restricted driving, the driving ban may also pose a considerable impact on employment and education and thereby economic status (Norekval & Vijgen, 2010). This was certainly the case for Rose who lost her job after her ICD as driving was an important part of her work role. The women who returned to work during their restricted driving period talked of having to navigate taxis and buses, or they did not adhere to the full driving restriction, either on their GP's advice or making this decision independently. Tagney et al. (2003) and Shea (2004) all found that driving restriction impacted on all aspects of recovery and adjustment to living with an ICD. These driving restrictions affected not just the ICD recipient but had repercussions for family and friends, placing an increased burden on all. Indeed Albarran and Tagney (2001) also found relationship conflicts over driving and role changes during the driving restrictions for ICD recipients.

Despite the difficulties and frustrations it caused, the majority of the women in this study chose to adhere to the recommended driving restrictions. Three, however, chose to drive against advice. These women were motivated to do this by the cost, time and physical exertion required to use alternative transport, and the logistical difficulties of getting to work or having no other driver in a family with several children. Many perceived themselves to be a safe driver anyway. Reluctance to accept driving restrictions and the difficulties involved in trying to adhere to them were also issues found in several studies on ICD recipients (Albarran & Tagney, 2001; Johansson & Stromberg, 2010; Mylotte et al., 2013). Failing to adhere to medically recommended driving restrictions is not a phenomenon unique to this population but has been found in several other populations, with similar reasons for non-adherence being identified (Johnson, 2002; Rudman et al., 2006; Unsworth et al., 2007).

Functionally and mentally the driving restriction had a significant impact on the experiences of the women in this study. This is in-line with other research on the effects of the driving restriction on the ICD population and their families, as well as research on driving cessation in the general population. The actual risk of accident and harm while driving a private car with an ICD seems to be lower than average, possibly because some ICD recipients modify and self-limit their driving behaviour, although legal driving restrictions remain in place. However, the actual harm and effect of the driving restriction on mental health, social interaction and household management is significant and frustrating for those it affects. This

was more prominent in the secondary prevention ICD women as their restriction was significantly longer. Many women were surprised at how difficult it was to adhere to the driving restrictions placed on them and the extent of the impact it had on their lives.

The impact of being a mother

In this study four women were raising dependent children, two as solo parents. All found parenting with an ICD to impact on both their experience as a mother and as an ICD recipient. They reported the multifaceted impact this had on their experiences and their children, across the many themes in this study. For example, Lisa explained, despite being critically unwell post a cardiac arrest, *“all I could think about was my kids”*. Yet the impact on mothering post a cardiac arrest and ICD implant is rarely discussed in literature and neither is the challenge parenting poses to recovery post an ICD implant. Little literature other than achieving and maintaining pregnancy with an ICD was found (Andersen, Oyen, Bjorvatn, & Gjengedal, 2008; Ngu, Hay, & Menahem, 2014). Although the maternal survival rate after a cardiac arrest is much higher than most cardiac arrest populations, maintaining a pregnancy through a cardiac arrest and ICD placement without a peri-mortem caesarean section is uncommon, with Jeejeebhoy et al. (2015) finding two reported cases in the literature. These studies have a technical and clinical medical focus, without exploring what pregnancy and parenting with an ICD means to women and how it affects them. Walker et al. (2004) recognised that a women’s identity as a caregiver and parent is threatened by actual and perceived limitations of the ICD and underlying heart condition. (Conelius, 2014) interviewed three women with an ICD, one mentioned that her young children bump her ICD site and the need to guard against this, however, this was the only reference to her as a mother. This study did reveal further experiences of mothers receiving ICDs, some of the issues raised will be discussed here further.

Three of the women in this study had young children who witnessed their cardiac arrest and resuscitation, which was stressful for all involved. Younger children were ill-equipped to understand what was occurring. Kate’s daughter thought her mother was being hit when her partner was resuscitating her and initially Kate felt her daughter *“wasn’t coping, going through that trauma”*, although this had since resolved. Tina’s children were older and were involved in calling for assistance, directing and debriefing emergency personnel, which Tina recognised was stressful for them. While research has explored the potential benefits of a family presence during resuscitation to their mental health and process of grieving, these studies focus on adult family members rather than children (Clark, Guzzetta, & O’Connell, 2013; Jabre et al., 2013).

All women received their ICD in a tertiary hospital, requiring them to leave their home district, sometimes for several months. The children of the women remained in the local district for the majority of that time, with family or friends providing childcare. Being absent from their dependent children was an additional stress for the mothers and a strong motivator to return home, with delays to discharge causing further distress. As Lisa explained *“I just cried and cried... I am going home... I haven't seen my baby”*. Only Kate, who was away the longest, had her young daughter come with her partner to stay in family accommodation at the tertiary hospital site. Her daughter was then able to spend substantial periods of the day with her in hospital. Kate valued this time with her daughter, *“so she wasn't going through it alone”*, feeling it was important to maintain her family unit and that this reduced her daughter's distress at witnessing her resuscitation. However, bringing their dependent children to the tertiary centre was not a viable option for the other women.

The children's experience of being separated from their mother was identified as being stressful and disruptive. Immediately post her cardiac arrest Lisa focussed on the welfare of her children by arranging childcare. She found herself forced to split her children between multiple households even though her children did not want to be separated from each other either, adding to her worry. Separation affected all family ties. Lisa was devastated by the disrupted bonding with her new baby and her older children after her absence to receive an ICD. Saying of her new baby,

After I came back, he wouldn't come to me and that really shattered me. (Lisa)

Detrimental effects on bonding can be found even after a short-term disruption to the mother and child relationship (Elmir, Schmied, Wilkes, & Jackson, 2012). Temporary childcare was necessary for all of the women, with family and friends providing support or taking the children. And even though only half were single parents, the partners of the other two women travelled with them to the tertiary hospital for support, limiting their capacity to provide childcare. Power, Jackson, Carter, and Weaver (2015) also found female friends and relations to be important in supporting children of mothers with an acute illness.

The medically imposed restrictions on arm movement post their ICD made many household chores more difficult for all women, but these mothers also had to consider how they would manage the practicalities of parenting their children. Kate had never picked up her son before she took him home at six months old, having only held him when she was sitting down. After their ICD implants both Kate and Lisa were the caregivers of an infant and had concerns about how they could lift and carry their child to provide care. Both women, however,

had a delay before being primary caregivers, Lisa as her female family members maintained this role for a few weeks and Kate as her son had a lengthy hospitalisation after birth. Kate successfully breast fed her son, although this and holding her son to her left chest was not comfortable due to the physical presence of her ICD in her upper breast. However, prior to her ICD, Lisa was not breast feeding her baby and she did not notice her ICD when in physical contact with her children.

Once home, being the primary carer for children required these mothers to continue with usual routines around parenting, as caring responsibilities and household tasks continued and could not wait, as Western society constructs the responsibility for children to be almost wholly in the mother's domain (Power et al., 2015). Children still needed to be fed, taken to school, to sports and to be loved. All of these mothers had a cardiac arrest prior to their ICD, which is often associated with impaired physical and mental function (Alexander et al., 2011; Lim et al., 2014). Gail described being "*barely able to walk from one end of the house to the other*" when she returned home to care for her child. She found that being a sole caregiver impacted on her recovery as "*with having [my child] around I had to get up and I had to do things*". This need to carry on, reflects the 'relentless responsibility of motherhood' and 'doing your best' themes found by Power et al. (2015) when they examined how illness impacted on women caring for a child in a mothering capacity.

The mothers in this study also found the six month driving restriction once they returned home added to their difficulties. Three of the women were the only drivers in their households, making this especially difficult. Initially to get her young child to school Gail organised complicated rosters of friends and childcare, before graduating to walking one way with her child and then taking a taxi home. As her physical function improved this became less problematic and eventually she was physically strong enough to take her child on the bus for outings. Lisa also found it difficult to manage her children's school, sports and appointments without a driver in the household. She felt the heavy burden that needing help with driving placed on her extended family and tried to minimise her family's requests for transport. Tina's oldest daughter conveniently gained her learner driver's licence during Tina's restricted period, so was able to provide some transport to grocery shopping and appointments.

Tina's older children were able to provide assistance, like driving and chores, while requiring less direct supervision and care. Whereas younger children required more support, all women felt their children were aware of their mother's ICD and health issues, discussing it with them at age appropriate levels. Some women had plans that they taught their children about what to do, like Gail, who taught her child how to press her medical alarm and ring an

ambulance if needed. Linder et al. (2013) found that children were a source of stress for ICD recipients, as parents with an ICD were concerned about children witnessing them receive a device shock. Gail found planning for this possibility to be reassuring for herself and her child. Though they did not clarify whether they referred to adult or dependent child, Kamphuis et al. (2004) reported that the expectations and lack of empathy from children still living at home was disappointing for some ICD recipients. However, the mothers in this study referred to their dependent and independent children as caring and helpful. Palacios-Ceña, Losa, et al. (2011) explored the experiences of male ICD recipients in Spain. Children were present in nearly a third of these households, although mostly over the age of eighteen. No comment on their impact was made. This may be due to cultural and gender differences in relation to childcare responsibilities or the generally older age of these children.

Linder et al. (2013) found that the desire to live to raise their children was particularly motivating for potential primary prevention recipients, prompting their ICD implant, with parenting or contemplating becoming a parent being an extremely influential factor in deciding to have an ICD implanted. These findings are consistent with this study as, all the mothers with dependent children valued their ability to parent and be present for their children's lives. This was poignant for these mothers as they had already survived a cardiac arrest and recognised that they could have died. They appreciated the extra time as an opportunity to raise their children and influence their lives. Providing a cultural grounding in language and identity to her children was important aspect of this mothering role for Kate, *"so they know where they are from and who they are"*. Women appeared to believe that the presence of a mother while they were still young would improve their children's future health and wellbeing. Because she saw how important her role as a mother was, Lisa chose not to add further children to her family and risk provoking a further cardiac problem as she could not justify dying and leaving another child or her existing family. McDonough (2009) also identified raising children as a concern for young adults with an ICD, especially solo parenting and the uncertainty of how children would cope and be taken care of if their parent died.

Parents with genetic disorders leading to their ICD were concerned that their children could inherit their disorder (McDonough, 2009). Like Lisa with Long QT, all parents with inheritable conditions in McDonough's study were proactive regarding testing for cardiac disease in their children.

Two of the four women with dependent children in this study had also experienced device complications requiring further hospitalisation and procedures, while another mother was waiting for further testing on a probable problem at the time of interview. These

complications, while carrying increased risk for the women, also required them to leave their family with little notice, which was inconvenient and a little frustrating.

Reviewing the literature on mothering with an illness, Vallido, Wilkes, Carter, and Jackson (2010) identified that a woman's identity as both a mother and a patient is often unacknowledged by healthcare professionals, leaving them reluctant to discuss the difficulties they had around mothering duties when ill. Although within the cancer population mothers with young children are most likely to have intrusive fears around disease recurrence (Arès, Lebel, & Bielajew, 2014). However, Vallido et al. (2010) believed that nurses are well-positioned to support mothers in illness by acknowledging the importance of this role and offering them support and opportunities to discuss the effect of their illness on their ability to mother. Power et al. (2015), Mackenzie (2014) and Semple and McCance (2010) all agree that mothers require additional consideration from healthcare staff to navigate their illness, which is likely to be true of the ICD population also.

Depression and emotional adjustment

The women in this study described a variety of emotional responses and attitudes experienced during their individual journeys with their ICD, with most reporting a tendency to move from negative to more positive feelings over the course of time. These women normally noted improvements in their moods as time passed after their implant, and associated part of this with increasing physical fitness and the lifting of the driving restrictions which enabled easier social contact. This improvement trend supports the findings of others (Kamphuis et al., 2004; Marshall, Ketchell, & Maclean, 2012; Morken et al., 2010). van den Broek et al. (2014), however, found the emotional trajectories of ICD recipients to be relatively stable after a small initial decline.

Three of the 14 women (21%) in this study spontaneously revealed they had been clinically treated for depression since their ICDs, either with new antidepressant medications or therapy. Others spoke of transient negative and low moods. Depression and anxiety are recognised as issues affecting the ICD population at higher rates than the general population. There have been multiple quantitative studies measuring these emotions, with rates in the literature ranging from 9-15% for depression and 13-38% for anxiety, although these studies are older and may reflect older technology and populations less comfortable with the technology in this form of intervention (Dunbar, 2005; Sears & Conti, 2002). The three women diagnosed with depression described the negative effect this had on their initial experience of living with an ICD. This negative effect on quality of life is also described in other studies and is even

associated with increased mortality (Lampert, Jain, Burg, Batsford, & McPherson, 2000; Pedersen et al., 2005). However, as studies on other chronic disease also found increased rates of depression and anxiety, these issues may simply be related to living with illness rather than life with an ICD (DeJean et al., 2013).

After an ICD implantation, decreased personal resources such as poor social support, poor physical function and a history of depression, can increase the risk of anxiety and depression (Luyster, Hughes, Waechter, & Josephson, 2006). Rose described loss of resources post her ICD when she said *“everything had been taken away”*. Certainly the secondary prevention ICD recipients in this study talked about loss, as loss of physical function, loss of social contact through work and hobbies as a result of the loss of the driver’s licence and loss of independence, all losses that may have significantly impacted on their emotional well-being. Of the women who reported having been diagnosed with depression, both Gail and Rose had ceased to work after their ICD and Jill keenly anticipated her slow return to work.

Several women in this study noted that time spent alone provided ample opportunity to dwell on death, contributing to negative and depressive thoughts. Rumination has been identified as an important component of depression and anxiety (Newall et al., 2007). Jill described the effect of rumination on reflection saying,

I think that was part of the problem before, I would sit there and think about it and worry about it and you become quite antisocial because you are too worried about dying. (Jill)

Recognising this tendency to ruminate prompted women like Ana and Jill to keep active, working and engaged in their community as they identified being busy as a useful technique for reducing the opportunity to dwell on death and ill health. Community connectedness and belonging to social groups is effective in reducing depression, so this attitude was likely to be helpful to these women coping with life post an ICD (Cruwys et al., 2014; Ding, Berry, & O'Brien, 2015).

The three women who acknowledged diagnosed depression had all received secondary prevention ICDs and struggled with reoccurring anxiety about death. Several studies have looked at which individuals are more likely to experience negative psychological issues, with some variable results. van den Broek et al. (2014) found ICD indication to be unrelated to emotional and physical distress, whereas Rahmawati et al. (2016) found primary prevention patients to have more anxiety, particularly around their device. Cardiac arrest patients, even

without reference to treatment with an ICD, have reported depression rates varying from 14% to 45%, with increased rates noted if cerebral hypoxia occurred (Wilder Schaaf et al., 2013; Wilson et al., 2014). Middelkamp et al. (2007) associated post arrest hypoxia with decreased cognition and daily functioning. Hypoxic brain injury is commonly found in the secondary prevention population. Of the women with diagnosed depression, only Gail reported early cognitive impairment that she felt was resolved by the time she returned home. Although all three women felt physically run down, none required physical support for activities of daily living and only minimal professional assistance with housework. However, Wilson et al. (2014) found decreased daily functioning made no difference to the quality of life in these patients, while other studies found it influential (Andersson et al., 2015; Moulaert, Wachelder, Verbunt, Wade, & van Heugten, 2010). However, the presence of a hypoxic brain injury, of any severity, could be seen as a co-morbidity and the presence of a co-morbidity increases the burden of psychological distress and physical dysfunction in ICD recipients (Hoogwegt, Kupper, Jordaens, Pedersen, & Theuns, 2013).

Depression and anxiety may be related to personality type. The tendency to experience negative emotions across time and to inhibit these emotions is a stable construct characteristic of Type D personality. Type D personality in the ICD recipient or their spouse have both been consistently associated with higher levels of depression and anxiety in the ICD population, with a Type D personality carrying a higher mortality risk for ICD recipients (Habibović et al., 2011; Mastenbroek et al., 2015; Starrenburg et al., 2013; Thylen, Dekker, Jaarsma, Stromberg, & Moser, 2014; van den Broek, Heijmans, & Van Assen, 2013; van den Broek, Nyklícek, van der Voort, Alings, & Denollet, 2008). These studies suggest that personality traits are more closely related to distress than situational or clinical issues. In this study, no assessment was made of the personality characteristics of the women interviewed, however, both Gail and Jill described themselves as “*a positive person*” when discussing their struggle with depression after their ICD.

Newall et al. (2007) found that levels of clinical depression (7%) and anxiety (13%) in New Zealand ICD recipients to be lower than international trends. The researchers postulated that the continuity of care and small team approach to the service that the surveyed population experienced, allowed positive relationships to form. They found a high degree of satisfaction with the support provided and felt this could have contributed to a low rate of psychological issues in their New Zealand ICD cohort. The women in this study certainly valued interpersonal relationships, with positive and close relationships with professional health carers being particularly noted and valued. These relationships were generally referred to as being accessible and making the women feel cared for and supported, although some women would

have preferred increased local health care support. Other qualitative studies noted that continuity of care and feelings of ongoing support were absent for ICD recipients, or that psychosocial concerns around ICD placement was rarely addressed by medical staff (Flanagan et al., 2010; Morken et al., 2010).

The effect of gender on psychological health post an ICD has been explored in several studies, with varying conclusions reached. A literature review by Brouwers et al. (2011) found insufficient evidence to conclude that gender can account for disparities in psychological distress. Most studies since then have also found no significant difference in depression rates between males and females (Miller, Thylen, & Moser, 2016; Starrenburg et al., 2014) . However, Rahmawati et al. (2013) reported a significant relationship between gender and depression. This may reflect slightly different populations and cultural differences between studies.

Female ICD recipients do experience higher levels of anxiety around defibrillator shocks and death than males, according to multiple studies (Miller et al., 2016; Sowell, Sears, Walker, Kuhl, & Conti, 2007; Spindler, Johansen, Andersen, Mortensen, & Pedersen, 2009; Starrenburg et al., 2014). Although Marshall et al. (2012) found that while women reported higher levels of anxiety on discharge, they also demonstrated significant improvement over time, as such that after twelve months men were reportedly more anxious than women, with younger ICD recipients and those who live alone being more likely to experience depression and anxiety (Friedmann et al., 2006; Thylen et al., 2014; Vazquez et al., 2008). Of the three women with diagnosed depression, two were the only adult member of the household although one was raising a dependent child and only one had experienced a defibrillator shock.

Emotional changes, especially anxiety and depression following an ICD, are commonly found across many studies including this one. A variety of reasons and risk factors have been explored around this phenomenon, including, gender, age, ICD indication and personality type, with the most consensus being on personality type affecting coping and psychological health and outcomes. The women in this study described improvements across time with increasing physical health and engagement with their community, essentially as life became more normal. This trajectory has been described in other literature also. The majority of women in this study were able to manage their emotional wellbeing independently or with support from established relationships including discussions with electrophysiologists and registered nurses. Only three of the women sought support from their GP.

Discussion on end of life care

This section will briefly examine how and why the women interviewed considered and conceptualized their eventual death, from confidence in their ICD to prevent death, feelings of immortality and issues arising from this and what the experience of dying could be like for them. Their possibility of dying with an active ICD will be discussed along with the option of device deactivation. Device deactivation is perhaps uncommon as knowledge regarding end of life care and the possibility of device deactivation is poor amongst ICD recipients as well as health professionals. Increased education about these issues may alter recipients' preferences and outcomes. Regular discussion about end of life options are recommended but rarely occur, as patients, families and medical staff tend to avoid the topic until the immediacy of end stage terminal disease prompts such discussions. As a result, the opportunity is missed for discussion, education and planning in a non-acute environment. What planning activities were undertaken will also be explored.

All those who live with an ICD have been medically assessed as being at an increased risk of dying as compared to the general population, even though the New Zealand guidelines for ICD implantation require device placement only in those with a likelihood of survival greater than eighteen months from other co-morbidities (W. Smith, 2010). Whether people have a primary or secondary indication for the device, the reason they have it is to prevent sudden cardiac arrest and death. All the women in this study seemed to understand the underlying function and purpose of their device was to help prevent their death. This was particularly clear for those with secondary prevention devices who had already had a cardiac arrest and therefore a near death experience. In the primary prevention group with CRT-D devices, this understanding was less overt as the CRT function was perceived as the main purpose of the device. However, receiving an appropriate shock from her CRT-D impressed upon Mere her device's secondary, death preventing capability.

Women with ICDs are therefore forced to consider and confront death. These women were also in the unique situation of doing so, with an ICD capable of reversing or aborting sudden cardiac death when or if it occurred. Most women, particularly those with secondary prevention devices, appeared to assume that death for them would be a cardiac arrest and therefore occurring suddenly at random. This was guided by their previous experience of cardiac arrest. Most women generally expressed confidence in their ICD to work if they had a lethal arrhythmia, whether or not it had yet been required to do so, however, many indicated

that at some point it might not be successful and therefore CPR might be tried or they would die.

This confidence in the device and assumed mode of death lead Rose to initially rationalise excessive alcohol consumption post her ICD, as she felt her ICD would save her from harmful consequences. Later she recognised that other medical problems could still result in permanent harm and death. This is important as an ICD prevents death from lethal cardiac arrhythmia but does not address or treat the underlying disease process. A CRT-D for heart failure, however, does affect the underlying disease process, improving cardiac function, improving individual morbidity as well as mortality (Mitar, Alba, MacIver, & Ross, 2012). However, ICDs are so effective at preventing death from cardiac arrhythmia that most ICD recipients will die from underlying heart disease or another terminal illness like malignancy (Lampert, 2014).

In this study only one woman, Vera, discussed contemplating her death as coming from anything other than a sudden cardiac arrest. This may have been because she was the oldest participant and had a progressively disabling non-cardiac condition. She recognised this condition as potentially terminal, and so had considered how life and death with this problem could occur. This deeper contemplation on mode of death lead her to conclude that, actually, a sudden death from cardiac arrest could be preferable to a drawn out and disabling death from other causes, despite this being actively prevented for her by her CRT-D. That only one of the women considered this is consistent with Matlock et al. (2011), who reviewed patients contemplating the implant of an ICD. In this study only one of twenty patients considered quality of life and the trade-off between dying quickly versus living longer with progressive heart failure.

Defibrillation shocks are also painful. All cardiac devices can be deactivated. They can be reprogrammed or an external magnet placed to disable the defibrillation function (Mitar et al., 2012). The deactivation of defibrillating shocks does not cause death but allows the natural path of incurable end-stage disease to occur, without the potential to experience painful shocks. Irreversible physiological changes can occur at the end of life, which also increase the risk of undesirable ICD shocks (Mitar et al., 2012). With an active ICD, arrhythmias and shocks are a common feature in the dying patient. Post mortem device interrogation revealed 31% of dying patients received a shock in the 24 hours before death, including many with arrhythmia storms, receiving more than ten shocks (Kinch Westerdahl, Sjoblom, Mattiasson, Rosenqvist, & Frykman, 2014).

Research suggests that many physicians feel uncomfortable discussing end of life plans with patients and that they also lack knowledge in device deactivation (Kramer, Mitchell, & Brock, 2012; Kraynik, Casarett, & Corcoran, 2014; Mitar et al., 2012). Concerns around the legality and morality of device deactivation is noted in several studies, particularly from America. Despite these concerns, device deactivation falls within issues concerning patients' right to autonomy. Patients have the right to make informed choices to accept or decline treatment. Even if treatment has previously been accepted, ongoing treatment can be refused (Kramer et al., 2012). Vera's awareness of her options and her informed consideration of her end of life care meant that she had planned for her future circumstances.

Hill et al. (2015) reviewed several studies and found diverse patient preferences regarding ICD deactivation. This may in part be due to patients' differing levels of understanding of their device's function. Groarke et al. (2012) found that, despite a careful pre-implant education intervention, many patients demonstrated a poor awareness of the function of their ICD, with over half erroneously believing that their ICD (not CRT) will improve breathing, exercise capacity and reduce their risk of heart attack. Dodson, Fried, Van Ness, Goldstein, and Lampert (2013) and Stewart et al. (2010) also found poor patient understanding of the benefits or potential burdens of their ICD as well as unrealistic expectations and misconceptions on the function of an ICD which may contribute to patient concerns around device deactivation. Females with an ICD were more likely to have insufficient knowledge on end-of-life issues. This was associated with indecisiveness when asked to make decisions about ICD deactivation (Stromberg et al., 2014). Certainly, device deactivation and end of life issues were rarely raised by the women in this study, despite many talking freely about death.

Awareness of an individual's understanding of their ICD, its role in end-of-life care and attitudes towards death and dying are important for ICD recipients to be able to make informed choices. Dodson et al. (2013) found, after giving patients an informational script on ICD function, the majority at 71% responded that they would want their ICD deactivated in various scenarios common in dying patients. This contrasted with prior investigations which suggested that the majority of patients would not want device deactivation even with advanced illness. Stewart et al. (2010) found 70% of patients indicated they would keep their device active if dying of cancer and 55% even if having daily shocks. It is possible that, as Dodson et al.'s (2013) study used an informational script, it not just informed participants of the possibility of deactivation but that going through the scenarios created a situation that helped them to consider and clarify their preferences (Matlock & Allen, 2013). However, consideration and clarification of individual's preferences requires informed discussions.

Two consensus statements, American and European, recommended discussion pre implant and ongoing regarding end of life care and device deactivation (Kramer et al., 2012; Mitar et al., 2012). Device deactivation is perceived as a difficult topic which should be raised when there is time to consider complex and emotional information, and to discuss an individual's personal preferences (Matlock & Allen, 2013). However, research suggests that these discussions are not well done. Kramer et al. (2011) found nurses believed that initial advance care planning discussions occurred infrequently and were rarely revisited as patients health status changed. This belief is supported by the findings of Niewald, Broxterman, Rosell, and Rigler (2013) who, in a review of 91 records on informed consent for an ICD, found only one documented an end of life discussion and this issue was raised by the patient. Some physicians report a knowledge deficit and feel less comfortable discussing device deactivation than other lifesaving treatments (Kramer et al., 2012; Sherazi et al., 2008). Interventions on improving this knowledge deficit and creating electronic forms and reminders in patients' records can improve outcomes, with deactivation in dying hospice patients increasing from 57% to 84% with these measures in place (Kraynik et al., 2014).

Vera was the only participant in this study who reported discussing death and dying specifically with their medical practitioner. She had completed and discussed a four page document around her wishes and expectations on dying with her GP and family and had previously explored how death could occur with a CRT-D with her implanting cardiologist. Vera found the opportunity to have these discussions and complete this form as "*lovely*" and "*very reassuring*". Having medical recognition and discussion around her mortality was valued by Vera but it was unclear if other participants had had the opportunity for this type of discussion also. This may reflect the general difficulties common around comfortably conversing about death, although death was discussed by all women when given time or asked specifically during this study. A few women, including Enid, Lisa and Vera, volunteered that death was spoken about freely in their family settings, between their spouse, siblings, children and themselves. Others, like Mere, acknowledged that talking about mortality and death was difficult with those you love. Fluor, Bolse, Stromberg, and Thylen (2014) found that spouses of ICD recipients felt that open and honest communication would help reduce uncertainty and promote coping when facing terminal illness, but actually that the role of the ICD was rarely discussed between spouses and healthcare professionals. Terminal illness is more likely to provide a trigger for conversations about device deactivation and palliative care (Goldstein et al., 2008; Mitar et al., 2012). However, conversations about care goals tend to occur so late in the patient's illness that their impact on care processes is reduced and often fail to provide patients with sufficient

information about their prognosis to allow appropriate decisions to be made (Bernacki & Block, 2014).

Health professionals need to acknowledge and communicate the presence of a terminal illness or the transition to palliative care to their patients. A missed opportunity for discussion on end of life preferences, information on projected disease trajectories and the subsequent role of the ICD, was clearly present for Ana, who reported that she discovered via the doctor's receptionist that she was listed there as receiving palliative care. This confused her and resulted in her feeling increased uncertainty around her future, but she still felt unable to raise the issue with her GP. This does not meet her rights to good quality communication and information when receiving a health and disability service (The Ministry of Health, 2014). However, it seems likely that opportunities were also missed and that discussions around death and dying did not occur for many of the women in this study. Palliative or end of life planning activities were being independently undertaken by some of the women in this study. Healthcare education and input into these activities could be beneficial, although these do not routinely address patients' nonmedical goals (Bernacki & Block, 2014).

Many women in this study had made practical plans for their eventual death and dying. These planning actions included assessing where they preferred to die, organising and buying plots in graveyards or choosing locations for ashes to be placed and planning funeral services. Many women were prompted in their contemplation of death to update and organise their wills and finances, to make their affairs easier to wind up by family. Women engaging in these activities had recognised and acknowledged they had a potentially life limiting condition and could die at any time. However, they all viewed these practical actions as being positive and taking control of the situation, rather than negative and morbid. These activities and plans around death and dying occurred independently and did not appear to involve any discussions with medical or nursing practitioners or healthcare staff.

Several women, like Lisa, perceived themselves as "*otherwise healthy*" apart from their increased risk of a lethal arrhythmia, so the opening and impetus for detailed discussions on end of life may seem less appropriate in their situation. However, early discussions about goals of care are associated with better quality of life and reduced use of medical interventions while actively dying and, while it is commonly believed that discussion about end-of-life issues increases patient distress, this is not supported by current research (Bernacki & Block, 2014). As many patients do not know their device could be deactivated, deactivation discussions often occur reactively when patients become too ill to participate in decision making or after multiple shocks (Kramer et al., 2011). Goldstein, Lampert, Bradley, Lynn, and Krumholz (2004) surveyed

next of kin of dead ICD patients and found that only 27% stated that the option of deactivating their relatives' ICD was discussed prior to their death, with most discussions occurring within the last days of life and 22% in the last hours. Of these patients, the majority at 78% chose to deactivate the device. The women in this study were independently undertaking activities planning for their eventual death and some had significant underlying heart disease and underlying chronic co-morbidities impacting on their life expectancy. It is suggested that they would probably have been receptive to end of life discussions and medically initiated future planning in at least some instances.

While the women in this study reached a state of acceptance about living close to death, how this was addressed and communicated to others varied. It appeared that most planning activities and discussions around mortality did not include healthcare staff. Greater involvement of medical staff on end of life planning, could increase knowledge around dying and end of life issues for this population and bring greater awareness of the options for device deactivation in the future. This could offer women with ICDs the opportunity to better plan for their future medical care needs.

Nursing and peer support for ICD recipients

Specialist nursing care post ICD implant was available to most women in this study. This support was based and initiated at the tertiary hospitals and could continue in the form of phone contact with a specialist nurse, this contact varied in frequency and over time between the two tertiary hospitals. These women also had regular electrophysiology visits for device maintenance every three to six months and occasional cardiologist appointments. Some women like Lisa, freely sought advice and support after they returned home, whereas others, particularly primary prevention ICD recipients found this unnecessary. Despite not all women in this study accessing ongoing support from specialist nurses, the therapeutic relationships they did form were overwhelmingly referred to as positive and valued, which helped the women to feel secure, cared for and they described this as helpful in navigating their experiences of receiving and living with an ICD. Establishing professional therapeutic relationship is beneficial with Morken et al. (2014) finding that while the majority (68%) of ICD recipients perceived constructive support from their healthcare professionals, perceived non-constructive support was associated with increased PTSD symptoms. Psychological issues like PTSD are associated with increased risk of receiving a shock from the ICD and higher rates of mortality (Dunbar et al., 1999; Habibović et al., 2012; Kikkenborg Berg et al., 2014).

Constructive support, that which is helpful and useful to the recipient, may be best provided by a specialist ICD/cardiac device nurse, as Norekval, Peersen, Seivaag, Fridlund, and Wentzel-Larsen (2015) found that overall generalist nurses lacked knowledge on key clinical issues on the care of ICD patients. This is consistent with an earlier study by Tagney (2004) which also found that general cardiology nurses knowledge of ICDs and their effects were poor, regardless of additional qualifications and time spent working as a cardiology nurse. These nurses were not confident in their ability to prepare patients for an ICD implant or life at home after the implant. This may mean that appropriate counselling and nursing care may not be provided and that ICD recipients might receive inaccurate or contradictory advice which could increase their uncertainty and potentially impact on their confidence once home. While ICD knowledge is not statistically linked to quality of life measures for ICD recipients, uncertainty is. Contradictory information is likely to increase uncertainty and therefore impact on quality of life (Norekval et al., 2015; Sossong, 2007). A specialist nurse should have advanced knowledge and skills and be able to help with discharge planning, reduce ICD related problems and educate on lifestyle changes (Bolse et al., 2005).

A specialist nurse would be ideally placed to provide needed psychosocial support to ICD recipients. Generally, technical aspects of the device dominate information given by healthcare providers with little attention given to the psychosocial aspects of living with an ICD (Kamphuis et al., 2004; Tagney et al., 2003). This is possibly because healthcare providers reported being most comfortable dealing with traditional medical issues like adherence to treatment and least comfortable with issues around emotional wellbeing, despite recognising this as a significant issue for ICD recipients (Sears et al., 2000). Raising psychosocial issues was also difficult for ICD recipients, in this study both Rose and Jill who were treated for depression found it difficult to articulated and describe their emotional difficulties, however, Jill's established relationship with her GP allowed her GP to recognise the need and prompt a psychosocial discussion. Morken et al. (2010) also reported this difficulty, plus noted that a lack of continuity of care undermined trust and made raising psychosocial issues more difficult.

Tagney et al. (2003) reported their participants felt an absence of appropriate support and advice post their ICDs. Rose's experience was congruent with this as she found herself regretting the absence of a local support group and unable to reveal her significant emotional difficulties over the telephone to the specialist support nurse at the tertiary hospital. Several other qualitative researchers have reported that their ICD recipients perceived specialist ICD nurses as useful in their recovery (Bolse et al., 2005; Flanagan et al., 2010).

Qualitative studies have shown that interventions by specialist nurses can improve patient experiences post an ICD. Dougherty, Thompson, and Lewis (2005) used a structured telephone nursing intervention for eight weeks post hospitalisation after an ICD implant, which showed substantial improvements in patient concerns, anxiety, fear of dying and knowledge, even though it had no statistical effect on hospitalisation over twelve months. Moulaert, van Haastregt, Wade, van Heugten, and Verbunt (2014) trialed a semi structured intervention for survivors of cardiac arrest, many who received ICDs, which was positively evaluated by patients, caregivers and nurses. They recommended offering at least two consultations per patient, beginning earlier rather than later after discharge home and using a formal screening tool for cognitive and emotional issues to facilitate appropriate referral and management. They also found that face to face visits were most valued.

Face to face follow-up and group support has been identified as beneficial in improving anxiety and mental quality of life, according to Sears et al. (2007), who compared weekly group education with the same information delivered in a block workshop. Group support in the form of participating in a specialised ICD rehabilitation program with a combined exercise training and psycho-educational intervention also improved mental and physical health (Berg et al., 2012; Berg et al., 2015). No face to face specialist nursing support was available to the women in this study, and group cardiac rehabilitation was targeted at ischemic heart disease, which although relevant to some of the women's cardiac history was not perceived as reflective or supportive of their ICD experiences.

Contact with peers when available was valued by the women in this study. Peer contact provided an opportunity to share and compare their experiences, this is reflective of other qualitative studies which found peer contact was desired, particularly with those with similar characteristics (Borse et al., 2005; Flanagan et al., 2010). All peer contact was made informally through family and community connections rather than through formal healthcare introductions, therefore, peer contact was not available to all of the women. The absence of peer support was regretted by some of the women, particularly Rose, as it made her feel more isolated and unusual.

Serber et al. (2009) found that for support and education female ICD recipients were likely to prefer the options of an ICD peer support group in addition to a phone call from a specialist device nurse, with women under 67 year old preferring internet peer support and web-based education. For the women in this study, however, these options were not readily accessible, only Jill talked about using the internet to learn about her ICD and research specific

concerns, another women was told there was a New Zealand Facebook group for ICD recipients but was not given the address or information to access this resource. How much benefit is derived from peer support groups is debateable, as Ussher, Kirsten, Butow, and Sandoval (2006) found that cancer support groups are perceived as providing a unique sense of community and acceptance by their participants, however, Salzer et al. (2010) found that despite positive experiences being reported, those participating in internet peer support groups did worse on psychosocial measures over time than the control group.

In this study Lisa reported reading and learning all the educational material given to her when she got her ICD, this knowledge was particularly important as it enabled her to subsequently inform medical staff about how to manage her ICD and surgery safely. Some women in this study reported feeling overwhelmed with information after receiving their ICD. Kate described information coming from multiple sources during her long hospitalisation, until she was uncertain which information was still relevant and why. (Eckert & Jones, 2002) recognised that ICD recipients can be inappropriately inundated with too much information at one time, but felt that open communication should be established early for continuous support and education. Several study's participants also reported that individualised information on recovery and discharge was lacking (Bolse et al., 2005; Fridlund et al., 2000; Tagney et al., 2003). Beth also reported this, she was grateful for her own healthcare background, as it helped her to navigate the written information she received and judge what information was relevant to her situation.

The women in this study reported variable levels of professional support and education pre and post their ICD. For some this met their needs well and others felt unsupported on discharge. A specialist nurse can provide accurate education and targeted assessment and support of psychosocial issues which are common post an ICD implant, this could improve the emotional experience, decreasing anxiety, fear and PTSD. The benefit of a specialist nurse is perceived as greater if the interventions begin early into the ICD process and face to face meetings occur. Additionally web based resources and support are perceived as useful especially by women, although they may not offer the same benefit. However, as the women in this study lived some distance from the tertiary hospital responsible for implanting their ICDs and providing the specialist nursing service, web based support may have increased accessibility.

Summary

Several issues raised by the women in this study have been discussed in depth. Overall these issues and experiences are supported by the literature, although there is very little literature on the impact being a mother had on life with an ICD. The issues the women described around discharge transportation home appeared to be unique also. The issues raised by the women in this study and discussed form the basis of the recommendations outlined in Chapter Six.

CHAPTER SIX

Conclusions

This research has provided a better understanding of how having an ICD impacts on women's lives in New Zealand. Using a qualitative methodology of semi-structured interviews, the broad experiences of women living with an ICD were explored, examining how an ICD affects them physically, socially and emotionally. The generosity of the 14 women interviewed made visible a wealth of experiences, both good and bad, that the women faced, as well as obstacles encountered in living with an ICD. Four main themes emerged from the experiences the women shared. These include the effect of antecedent events, physical device realities and practicalities, the positive value placed on interpersonal relationships and death or contemplating/considering mortality. Within these, several issues with relevance to nursing practice have been analysed in greater detail. These included, discharge planning, driving restrictions, return to physical activity, the emotional impact of the ICD, the impact of mothering and contemplating death.

Overall the results and issues highlighted in this research are reflective of those found in other studies. However, the impact on mothering post a cardiac arrest and ICD implant is infrequently described, as is mothering's effect on recovery post an ICD. The four women with dependent children in this study found parenting to impact on their experience as a parent and as a patient with an ICD. Another significant novel issue raised in this study was the negative experiences associated with having to travel to and from a tertiary hospital, both in terms of removal from and/or significant disruption to their usual support networks and in the transition to home following the ICD implant.

From the experiences reported by the women interviewed, it is suggested that improvements in the initial experience of living with an ICD could occur if more attention was given to the transition process from hospital to home. Several women were required to travel long distances alone on public transport post their ICD, which they found mentally and physically difficult. Physical deterioration in strength and stamina were a problem for the women with secondary prevention ICDs, making completing household activities more difficult, as did the medically indicated limits on arm movement. Several of the women with secondary prevention ICDs report being unprepared and professionally under supported to manage easily in their home environments. A closer focus on discharge planning and support could improve the initial experiences on transition home from hospital with an ICD.

Driving restrictions post their ICD had a significant multi-faceted impact on the experiences of the women in this study. Not being able to drive limited the women's independence in managing important aspects of their lives, including household shopping, medical appointments, social activities and attending to children's needs. Negative emotional and social consequences of these limitations, specifically isolation, depression, loss of autonomy and independence, placed an additional burden on the women studied and their families.

Many of the women in this study were uncertain about returning to their usual physical activities and with finding levels of exertion they were comfortable doing. Targeted and individualised support and education around physical activity, and how to manage this with an ICD, could improve beneficial activity levels for ICD recipients and help clarify medical ambiguities about what should or should not be restricted. This could be achieved through a consistent and communicated message to the ICD recipient and their wider healthcare team and support within a rehabilitation setting. This will improve physical and mental health.

Emotional changes following an ICD, especially experiences of depression, are found across many studies including this one. The majority of women in this study were able to manage their emotional wellbeing independently or with support from established relationships including discussions with electrophysiologists and supportive nurses. Only three of the women sought support from their GP. The women in this study described improvements over time with increasing physical and mental health and engagement with their community, essentially as their lives became more what they considered to be normal.

The women in this study achieved some acceptance of living closer to death. Women planned for events post death, but it appeared that most planning activities and discussions around mortality did not include their health care team. Greater involvement of health care staff on end of life planning could increase ICD recipient's knowledge around dying and end of life issues, bringing greater awareness of the options for device deactivation and management in the future. This could offer women with ICDs an opportunity to better plan for their future medical care needs.

This research allowed the opportunity for women's experiences to be recorded and heard. It contributes to existing national and international understanding of the experiences of women living with an ICD and could be used by health care services to plan for and provide more appropriate and relevant support for this population.

Limitations

Limitations of the research include the following.

- The participants chose to be interviewed, which meant that the group who participated felt they had something to say. The opportunity to talk about their experiences may appeal more to those with issues or difficult experiences around their ICD. This concept is supported by a voice message left for the researcher, politely declining to participate,

I honestly don't think I have got anything to contribute that would help... It [ICD] just does its thing. I forget I have got it. I'm grateful for it of course, but I really don't think I am the one you are looking for. (Voice message from potential participant)

- The results only reflect what the participants were willing to share about their ICD and their experiences of living with it. The questions were intentionally broad to enable the sharing of a wide range of experiences but the data was gathered via one-off interviews which limited their focus and the development of a relationship with the researcher to enable deeper levels of disclosure.
- In qualitative research, generalisation of results to the total population is not desirable or achievable. Trustworthiness and credibility are established partly by considering the transferability of the results, to see if they resonate with other women with ICDs. In this study however, no participants wished to review the initial findings, although the results resonated with the pilot participant with an ICD. Increased participant peer review may strengthen the findings.
- All participants were located within one regional health board in New Zealand, so the reported experiences of the women may not be shared by those from other geographical areas.
- The size of the academic project was a limitation for a sole researcher undertaking academic study with limited time and resources, given the broad scope of the research which aimed to give an overview of New Zealand women's experiences with an ICD.

Strengths

The following strengths of the research are highlighted.

- A high proportion of the women who received the initial invitation to participate in this research accepted the invitation. This highlights their keenness to share their experiences and the topical and relevant nature of the issues they raised.
- While the number of participants in the research was small, it included women from a wide range of ages and who represented a variety of employment statuses and family compositions. Māori women were well represented.
- The participants were particularly generous in sharing their unique experiences with the researcher. This resulted in a large amount of rich and varied data for analysis.
- No other qualitative studies have focuses on women with ICDs in New Zealand.

Recommendations

Many recommendations can be drawn from this study.

Recommendations for further investigation

- An investigation needs to be done into the issues around patients' fitness to drive following an ICD and shock, with a view to reviewing the current New Zealand guidelines around driving restrictions. There is the potential to align the New Zealand guidelines with the less restrictive European Guidelines on driving restrictions, having a positive impact on the lives of those with ICDs.
- The issues highlighted in this research indicate that there is further scope for research into the impact the responsibility of parenting has on a patient post a cardiac arrest and/or an ICD implant, especially women's role of mothering.
- Important knowledge could come from further investigation into the impact the mode and length of travel home has on physical and psycho-social health of ICD recipients and adjustment once home.
- Further research into advanced care planning in ICD recipients, and considerations related to device deactivation should be explored.

Recommendations for nursing practice

Specialist nursing role:

- Many of the recommendations related to pre and post implant and discharge planning could be coordinated and implemented by a specialist ICD nurse. Particularly education and continuity of recipient experience could be

addressed by a nursing role such as this. Specialist nursing roles are common in tertiary centres, however, this research highlights that regional centres have increasing ICD recipients who have arguably greater needs due to their geographical isolation.

- Increased education and awareness for all nurses about the experience of living with an ICD, especially as there are few specialist nurses in this field in New Zealand and the devices are becoming increasingly prevalent.

Pre- implant information:

- Information about post implant restrictions and advance care planning should be included when consent to receiving an ICD implant is obtained, resulting in better informed choices and open discussion. Women, particularly primary prevention recipients, will be better placed to activate support networks and plan in advance for how they will manage these restrictions.

Discharge planning post ICD should consider:

- Physical and cognitive function may be impaired. While these impairments may not be overt in a supported hospital environment, an unsupported home environment could be challenging, particularly in the secondary prevention population. Formal functional testing could be informative in some situations allowing deficits to be identified and addressed.
- Individualised information on medical restrictions, both short and long term, should be provided so that ICD recipients are not overwhelmed with extraneous information.
- Additional assessment and provision of formal home help via the health board would ease the transition home for many women. Women usually contribute the most to household activities and are limited post ICD in what activities they can do, with the medical restrictions on arm movement and the decline in functional capabilities experienced by the secondary prevention population.
- Thorough and early assessment of an individual's home environment and needs, so home environment modifications and care is in-place before the ICD recipient returns home, will make this transition smoother. This is particularly important for secondary prevention ICD recipients who may have new physical and cognitive deficits.

- Transport home from tertiary hospitals was physically and mentally difficult for many of the women in this study. This should be considered when determining what mode of transportation is to be used and how well supported on the journey the ICD recipient is likely to be.
- Early assistance or referral to be assessed for discounted transport vouchers would be beneficial, as driving restrictions made accessing practical and social activities difficult and public transport did not easily meet women's needs initially. This is particularly relevant for secondary prevention ICD recipients as they have the longest driving restriction.
- Parenting, its impact, the physical and mental demands on the ICD recipient once home should be considered when assessing women's support needs.
- An activity plan, with recommendations around how much and how to achieve this, would help promote health behaviours and attitudes towards exercise with an ICD. An out-patient cardiac rehabilitation class may provide a supported environment in which to re-commence activity. A return to work plan may also be helpful.

Post discharge:

- Ongoing professional support should be available post discharge. This support should extend to the spouse or support network of the ICD recipient, to maximise the informed support available to the recipient and aid in the transition from hospital to home. As post hospital discharge many ICD recipients and their support networks have ongoing questions and concerns, requiring emotional support and practical advice. A relationship established prior to discharge from hospital may make this more therapeutic and accessible.
- Engaging in social activities should be encouraged. Access to information on peer support networks would be valued by some ICD recipients and could be offered by offering contact information to existing national internet based ICD groups and potentially linking interested local ICD recipients

Advanced care planning

- Death and dying in the context of the ICD and preceding events should be addressed early and ongoing discussion encouraged.

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APPENDICES

Appendix 1: Letter of introduction to potential participants



Nicola Craig RN



Dear

My name is Nicola Craig and I am a Registered Nurse working in the Cardiology Department at the [REDACTED]. I am also doing a Master of Nursing degree at EIT and the research for my thesis is about women's experiences of living with an ICD. I would very much like to talk with you about the impact that having an ICD has had on your life.

Could you please help me with my research? It would mean meeting with me for an informal interview that would take about half an hour or talking with me over the telephone. I have enclosed more detailed information about the research and what it would involve.

I would love to hear from you. Please contact me or leave a message on [REDACTED] [REDACTED], or email me at [REDACTED]. I will be more than happy to answer any questions or concerns you may have about the research and your participation in it.

Thank you very much.

Yours sincerely
Nicola Craig (RN)

Appendix 2: Information for Research Participants



Information for Research Participants

Date: 1/10/2015

Project Title: What are patient's' experiences of living with an implantable cardiac defibrillator?

To:

Researcher(s): Nicola Craig

Affiliation: Student EIT: Master of Nursing

Description of the research:

This research aims to find out what it is like to live with an ICD. As the researcher I will interview people who have had an ICD for more than six months and ask them to recount their experiences. The purpose of this research is to find out how healthcare services could provide better information and supportive services/care to enhance the quality of life and adjustment post an ICD implant.

What will participating in the research involve?

If you agree to participate in this research you will be invited to discuss your experiences of living with an ICD with the researcher. The interview will take approximately one hour and will be audio recorded with your consent. The interview will be conducted in person or over the phone at a time and place that is convenient to you.

What are the benefits and possible risks to you in participating in this research?

In participation in the research you will have the opportunity to talk about issues that are important to you regarding your ICD and related concerns. You will contribute greatly to the knowledge and understanding of what it is like to live with an ICD. You and others may benefit from this knowledge, and from the increased healthcare services that may arise as an outcome of this research. If negative or unsettling concerns arise during the interview you will have the opportunity to request that a referral be made to an appropriate health care service.

Your rights:

- You do not have to participate in this research if you do not wish to.
- If you are a patient or under the care of students or staff from EIT, you can withdraw from the research at any time and this will not affect your treatment or assessment in any way.
- Once you have completed the research you have a week within which you can withdraw any information collected from you.
- You are welcome to have a support person present (this may be a member of your family/whanau or other person of your choice)
- You may request a summary of the completed research

Confidentiality:

The information you provide for this research will be treated as confidential. The interview will be recorded only with your signed consent and the electronic copy of this recording will be stored as a password protected file and be accessible only to myself as the researcher and

my supervisors. To protect your anonymity your name will be removed from all notes and transcripts and pseudonyms will be used when reporting the data. Other details which could potentially identify you will be deleted or obscured. Identifiable information about you will not be made available to any other people without your written consent.

If you wish to participate in this research, or if you wish to know more about it, please contact

Contact Person:	Nicola Craig		
EIT School/Section:			
Work phone #		Email address	
Mobile phone #			

Supervisor Name(s): (if applicable)	Dr Shona Thompson		
Work phone #	(06) 9748000 ext. 6116	Email address	sthompson@eit.ac.nz

Head of School/Manager:	Associate Professor Thomas Harding School of Nursing		
Work phone #	(06) 9748000	Email address	

For any queries regarding ethical concerns, please contact:
Chair, Research Approvals Committee, EIT. Ph. 974 8000

This study has been approved by the EIT Research and Ethics committee on 28/9/2015 Reference # 20/15.

This study has been approved by the [redacted] Health Board Research Office on 18/9/2015 Reference # 15/9/212.

Appendix 3: Consent form



CONSENT FORM

Project Title: **What are patients' experiences of living with an implantable cardiac defibrillator?**

Researcher: Nicola Craig

I have read and I understand the Information for Research Participants sheet dated 1/10/2015 for volunteers taking part in this study. I have had the opportunity to discuss this study and am satisfied with the answers I have been given.

I understand I am able to withdraw all of my information up to two weeks post the interview. I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the testing at any time and this will in no way affect my treatment.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had time to consider whether to take part, and know who to contact if I have any questions about the study.

	Yes	No
I agree to take part in this research		
I consent to my interview being audio-taped	.	.
I wish to receive a summary of the results	.	.

Signed: _____

Name: _____

Signature of Research Participant's Support Person (if applicable)

Date: _____

Witness: _____

I/We as researcher(s) undertake to maintain the confidentiality of information gather during the course of this research.

Signed _____

Dated _____

This study has been approved by the EIT Research and Ethics committee on 28/9/2015 Reference # 20/15.

This study has been approved by the _____ District Health Board Research Office on 18/9/2015 Reference # 15/9/212.

**District Health Board Location details – redacted
preserving participant anonymity**

10th September 2015

Nicola Leanne Craig
Research Coordinator

Tēnā Koe Nicola,

RE: “What are patient’s experiences of living with an implantable cardiac defibrillator”

Thank you for the opportunity to review your application for the above clinical research trial.

The Maori Health Service is happy to support the research above. If you require any assistance in regards to engagement with Maori participants, then please contact [REDACTED], Service Manager Maori Health Service on [REDACTED].

We look forward to receiving a copy of your research findings.

Noho ora mai rā

[REDACTED]

[REDACTED]

Kaiwhakahaere
Māori Health Services

[REDACTED]

Appendix 5: Eastern Institute of Technology research and ethics approval



Reference Number 20/15

28 August 2015

Nicola Craig
Masterate Student
C/- School of Nursing
EIT

Dear Nicola

I am pleased to inform you that your research project "*What are patients' experiences of living with an implantable cardiac defibrillator?*" was received and approved by the Research and Ethics Committee at their meeting held on 28 August 2015.

Part A of your Low Risk Questionnaire 20. Conflict of Interest

You have declared a conflict of interest.

How is this being addressed? and why do you think there is a conflict of interest?

Please provide clarification to the Committee.

You are reminded that should the proposal change in any significant way, then you must inform the Committee. Please quote the above reference number on all correspondence to the Committee.

The Committee wishes you well for the project.

Yours sincerely

Jeanette Fifield
Secretary – Research Ethics & Approvals Committee

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Appendix 6: Response to EIT research and ethics committee

Reference number 20/15

14/9/2015

Research Ethics and Approvals Committee,
EIT
Jeanette Fifield - Secretary

Thank you for the committee's review and approval of my research project "*What are patients' experiences of living with an implantable cardiac defibrillator*".

Low risk Questionnaire: Question 20 clarification.

20. Conflict of interest situation for the researcher (e.g. is the researcher also the lecturer/teacher/**treatment-provider**/colleague or employer of the research participants or is there any other power relationship between the researcher and the research participants?)

I am employed as a registered nurse in the inpatient cardiology service and may therefore have had prior or future contact with potential participants in this role.

This is one of the reasons my selection criteria includes ICD placed for more than 6 months, to provide timing distance from personal contact in my employment with potential participants and recruitment. As patients who have a secondary prevention ICD post a cardiac arrest may have spent several weeks in an inpatient cardiology unit.

I have previously discussed this potential issue with my Clinical Charge Nurse and with patient care allocation system utilised in my workplace I will be able to swap patient loads to avoid direct care of participants who are re-admitted if this is required.

Participant's rights as specified on the information to participants form include:

- You do not have to participate in this research if you do not wish to.
- If you are a patient or under the care of students or staff from EIT, you can withdraw from the research at any time and this will not affect your treatment or assessment in any way.
- Once you have completed the research you have a week within which you can withdraw any information collected from you.
- You are welcome to have a support person present (this may be a member of your family/whanau or other person of your choice)
- You may request a summary of the completed research

All of which I believe will adequately manage any potential conflict of interest.

Yours Sincerely
Nicola Craig

Appendix 7: Institutional approval

18 September 2015

Institutional Approval

Nicola Craig
[Redacted]

Dear Nicola

RE: [Redacted] District Health Board Research Application - Reference 15/09/212

Thank you for your application to conduct research within the [Redacted] District Health Board. The Research Office has had the opportunity to review your study and has given approval for your research project to be conducted within [Redacted]

This Institutional Approval is dependant on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study.

It is your responsibility to ensure you have kept Ethical Committees (as required) and the Research Office up to date and have the appropriate approvals. [Redacted] approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any amendment to study documentation
- Study completion, suspension or cancellation

Conclusion of your Research

At the conclusion of your research you will be required to provide a written report of your research findings to the [Redacted] Research Office.

Please find enclosed a signed copy of your application. Should you have any queries during your research, please do not hesitate to contact me during normal working hours.

Regards

[Redacted Signature]

[Redacted]
Nurse Consultant
On behalf of the
[Redacted] **Research Office**

Appendix 8: Interview Guide

Interview format for “What are patient’s experiences of living with an ICD?”

Intention is to ask participants to talk about the changes that may have occurred in their lives since receiving an ICD including; daily activities, work and leisure, relationships with family, friends and colleagues, attitudes towards body image, physical abilities, vulnerability and mortality. Any information or support systems they find helpful.

Introduction/icebreaker:

Introduce self and purpose/focus of research.

EXPLAIN AND SIGN CONSENT

So I am aware that you have an ICD, how did that come about? (Demographics)

The purpose of the interview is to look at any impact it has on how you live day to day.

Semi structured interview guidelines:

- How has having an ICD impacted on your life?
 - Prompts for areas to cover:
 - Relationships/family
 - Job
 - Leisure activities
 - Travel
 - Mood
 - Physically
 - Have you experienced any healthcare challenges
- What information/support is available to you/who do you talk to?
- What has been good about having an ICD?
- Any concerns or negative impacts re living with an ICD?
- Has it altered the way you think about life/death or how you live your life?
- Have you ever received a shock from your ICD?
 - If so would you like to tell me about that experience?
 - Did it change how you feel about your ICD?
- Is there anything else that you would like to tell me?

Conclude interview:

Thank you very much for taking the time to speak with me.

If you have any other concerns, questions or something to add, please feel free to contact me again.