PHENOMENOLOGY OF IMPLANTATION:

THE LIMINAL BODY AND THE IMPLANTABLE CARDIOVERTER DEFIBRILLATOR

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A thesis submitted in fulfilment of the requirements of the degree of Doctor of Philosophy

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THE LIMINAL BODY
To prevent sudden cardiac death as a result of fatal arrhythmias, over 1155 implantable cardioverter defibrillators (ICD) were implanted in Australians, in 2001. This represents an increase of 125% in the number of ICDs used in Australia since the previous survey, conducted in 1997. This rapidly expanding biotechnology remains poorly understood by recipients, their family members and by health professionals. Studies of both the effectiveness of ICDs, and their acceptability to patients, have provided equivocal results. Insufficient in-depth research exists to provide direction to health professionals involved in ICD implantation or to provide assistance to recipients and their family members in their decision-making.

This study focused on the phenomenon of implantation of a person’s heart with a permanent bioelectronic ICD. Implantation was explored through the existential perspectives of participants from four groups: recipients of ICDs, family members of recipients; cardiac nurses and paramedical personnel; and cardiologists.

Hermeneutical phenomenology was considered an appropriate methodology through which to explore the research question because of the humanistic approach that locates implantation within the context of the human Being. Methods of inquiry included unstructured in-depth dialogue, thematic analysis of participants’ lived-through experience, and interpretation by drawing on literature, poetry, art, and idiomatic usage of words relating to the heart. Six themes emerged from the dialogue of the key players in heart implantation with an ICD: implantation as body-liminality; implantation as body-temporality/time; implantation as body-spatiality/movement; implantation as body-emotionality; implantation as body-sexuality/gender; and implantation as body-relationality. After intensive reflection on the existential themes in this study it was necessary to move into a higher level of analysis that would complete the phenomenological journey. The phenomenological journey extended from exploring the phenomenon of heart implantation with an ICD to an understanding of the phenomenon as liminal-Being.
The findings from this research are expressed in terms of how participants experienced liminality in many existential ways. The phenomenon of implantation in relation to implanting the heart with an ICD, is an experience of liminality for recipients of the biotechnology in the context of ‘Being on the threshold of life and death.’

This project provides knowledge that existential-needs such as, indelph education, informed consent, negotiation, and support, experienced by the key players within the four groups, are not always met. The journey of this thesis identified a continuous thread of body-liminality experienced by all participants, albeit in differing ways. Collaboration between all players in heart implantation within the context of support groups is a strategy worthy of consideration within a healthcare system that appears more involved with bioelectronics than humanity.
ACKNOWLEDGMENTS

It is a privilege to thank some very special people who have taken part in this journey of research. This work belongs to all who gave of their time and support.

Especial thanks to all participants in this study: the recipients of implantable cardioverter defibrillators, the family members, the cardiac nurses and paramedical personnel, and the cardiologists. This study would not have been possible without them.

Associate Professor Marianne C. Wallis who believed in this project. Thanks for your staunch support and for sharing each endeavour associated with the study. As principal supervisor, for extending your vast knowledge, experience, and expertise: these attributes assisted in shaping this work. As a mentor, for being there and allowing me to discover myself as a researcher, your influence was invaluable.

Dr Winsome St. John who was always enthusiastic and challenging. As associate supervisor, for always maintaining involvement and encouragement. Diligent attention to detail has contributed greatly to this project.

Professor Anne McMurray, who gave up valuable time to be an independent reader of this work: the positive feedback and encouragement was much appreciated.

My friends who stayed alongside me and offered fresh perspectives: my humble thanks.

To my loving family: You are the wind beneath my wings.
STATEMENT OF ORIGINALITY

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Signature

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</tr>
<tr>
<td>Bradyarrhythmia</td>
<td>Irregular cardiac rhythm &lt; 60 beats per minute that cannot sustain the cardiac function.</td>
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<tr>
<td>Bioelectronic/biotechnology</td>
<td>Relating to medical devices and equipment requiring electronic circuitry.</td>
</tr>
<tr>
<td>Cardiac</td>
<td>Pertaining to the heart.</td>
</tr>
<tr>
<td>Cardiac Ablation</td>
<td>During electrophysiology studies the electrical cardiac cells causing arrhythmias are destroyed using radio frequency burning.</td>
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<tr>
<td>Cardiopulmonary Resuscitation (CPR)</td>
<td>“Protection of the brain by restoring its flow of oxygenated blood, with cardiac massage and artificial ventilation” (Thompson &amp; Webster, 1992, p. 203).</td>
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<td>Coronary Care Unit (CCU)</td>
<td>A specialist unit within a hospital rendering care to patients diagnosed with a life-threatening cardiac illness.</td>
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<tr>
<td>Electrophysiology Study (EPS)</td>
<td>Catheters are directed through veins to various areas of the heart. Arrhythmias are induced for analysis.</td>
</tr>
<tr>
<td>Implantable Cardioverter Defibrillator</td>
<td>A bioelectronic device that senses, paces, records, and delivers electric shock to revert potentially fatal cardiac arrhythmias.</td>
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<td>-------------------------------------------</td>
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<tr>
<td>Intensive Care Unit (ICU)</td>
<td>A specialist unit within a hospital rendering care to patients diagnosed with a life-threatening illness.</td>
</tr>
<tr>
<td>Life-world</td>
<td>All the immediate experiences, activities, and interactions that make up an individual’s world.</td>
</tr>
<tr>
<td>Nurse</td>
<td>Person with a current licence to practice nursing within Australia.</td>
</tr>
<tr>
<td>Ontology</td>
<td>Dealing with the nature of Being.</td>
</tr>
<tr>
<td>Ontic</td>
<td>Philosophy relating to real as opposed to phenomenal existence.</td>
</tr>
<tr>
<td>Patient</td>
<td>Person who is in need of medical or nursing attention for a life-threatening illness.</td>
</tr>
<tr>
<td>Sudden Cardiac Death (SCD)</td>
<td>Sudden cessation of cardiac function that begins the dying process.</td>
</tr>
<tr>
<td>Tachyarrhythmia</td>
<td>Irregular cardiac rhythm &gt; 100 beats per minute that cannot sustain heart function.</td>
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KEY TO EXCERPTS

In this thesis excerpts from the dialogue with research participants and excerpts from other sources of dialogue will be presented. Where necessary to enhance the flow of dialogue, to illustrate difficulty with expression, or to edit dialogue, various mechanisms have been utilised.

… An ellipsis is inserted where the speaker paused.

(…) An ellipsis in brackets was inserted when words were deleted by the researcher to edit out irrelevant dialogue.

(dialogue) Round brackets indicate the researcher inserting a definition or to expand an abbreviation.

[dialogue] Square brackets indicate the researcher inserting words either to assist the reader’s comprehension or to maintain the participants’ confidentiality.

*Emphasis* Italics was used by the researcher to indicate instances where the dialogue of the participant was elevated beyond normal speech.

**UPPER CASE** Upper case was used by the researcher to indicate extreme emphasis in dialogue by the participant.
CHAPTER ONE

LINKING TO THE PHENOMENON OF CONCERN

INTRODUCTION

During my nursing career I have been involved in nursing people who have been seriously ill in specialty areas, such as intensive care units (ICU) and coronary care units (CCU). All these seriously ill people had various forms of biotechnology attached to and/or implanted within their bodies. Specifically in ICU, ventilated patients are administered drugs according to a protocol every hour. One of the purposes for such a protocol is to prevent the patient ‘fighting’ medical treatment and to prevent the possibility of interfering with biotechnology. On admission to the cardiac area the first invasive intervention experienced by the patient is the insertion of an intravenous cannula. This ensures that health professionals have access to the patient’s internal body in the event of a life-threatening situation. These scenarios are not confined to ICU/CCU.

Most registered nurses have encountered patients who, even in a state of confusion, somehow know that biotechnology within the body is not a part of their body. These patients display this implicit knowing in ways such as, pulling on indwelling catheters and removing intravenous cannulae. I have a high level of respect for bioelectronics and biotechnology, and the therapeutic intentions from which medical technology developed. However, based on my observation of human beings in their illness situation and their reactions to bioelectronics, such as pacemakers and implantable cardioverter defibrillators (ICD), implantation of the body continues to hold my attention and my concern.

An ICD delivers internal electric shock therapy within the heart to treat heart arrhythmias that cannot sustain the heart in its function to provide the body with blood carrying oxygen. It is, as such, a potentially life-saving biotechnology implanted to reverse life-threatening cardiac arrhythmias. However, each time the ICD discharges,
patients receive a shock, they may fall to the ground, they may lose consciousness, and/or they may lose control of their bladder and bowels (Appendix A). Implantation of a person’s body leads me to wonder: What of people who have their hearts and bodies permanently implanted with bioelectronics, such as pacemakers and ICDs? How does a person deal with the primordial human urge to remove from the body that which is ‘other’? How can those involved in implantation of the human heart reach a deeper understanding of this phenomenon?

My intention in this project is to explore the phenomenon of implantation in the context of heart implantation with an ICD. The objective of the exploration is to develop an understanding of such a phenomenon by focusing on the body-perspectives of a variety of individuals. A person’s body-perspective aligns with Maurice Merleau-Ponty’s (1962) philosophy that human beings experience all phenomena through the lived-body. Wherever it appears fitting in the text of this project I will use first person tense because I am part of this exploration; as a socio-cultural Being, as a cardiac patient, as a cardiac nurse, and as a cardiac researcher. Merleau-Ponty’s existential phenomenology of the perceived body entitled, Phenomenology of Perception (1962) is of vital importance to this study of heart implantation. His account of bodily phenomena contradicts the objectified experience and alternatively embodies the subjective or lived-through events of the body.

**Linking to the phenomenon as a socio-cultural Being**

Socio-cultural meanings essentially shape the ontology of the human Being (Crotty, 1998). Expression of socio-cultural language shapes ways of knowing, ways of understanding, and ways of defining our humanness. For these reasons I chose a visual representation of implantation to shape this study.

The first page of this thesis is a photograph of a chest x-ray. This photograph is part of the ontological expression of May, a recipient of an ICD who participated in this study. May perceives that this photograph defines her. The photograph is entitled The Liminal Body.
Liminality is discussed extensively in later chapters as a thread that courses throughout this study. May was so overwhelmed by the evidence of her body and heart implantation, she was desperate for validation. Intuition prompted me to ask during our dialogue, “Would you mind showing me your x-ray?” May eagerly responded, “I have been dying for you to ask me.” Thus, we shared a powerful moment as socio-cultural Beings where we gazed upon the reality of scientific hybridisation of cybernetics and the human heart. The phenomenon I sought to explore was shown to me, captured by sophisticated biotechnology of the same type involved in this study.

As socio-cultural Beings, many people believe that the heart symbolises the central Being or soul of a person. Symbolic phrases referring to the heart that appeal to our consciousness as meaningful Beings are prolific. Table One: Heart understandings in classic/contemporary culture, provides some of the idiomatic uses of the word ‘heart’ and is adapted from the English Oxford Dictionary (Pearsall & Hanks, 2001). Being aware of the meanings that people associate with the heart will assist with understanding how implantation of a person’s heart with a permanent bioelectronic ICD can impact upon all who are involved in implantation.
Table One: Heart understandings in classic/contemporary culture

<table>
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<th>Heart:</th>
<th>A hollow muscular organ that pumps the blood through the circulatory system by rhythmic contraction and dilation.</th>
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<td></td>
<td>- The region of the chest above the heart: <em>holding hand on heart for the Pledge of Allegiance</em></td>
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<td>- The heart regarded as the centre of a person’s thoughts and emotions: <em>hardening his heart; he poured out his heart to me; he has no heart</em></td>
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<td>- One’s mood or feeling: <em>they had a change of heart; they found him well and in good heart</em></td>
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<td>- Courage or enthusiasm: <em>they may lose heart; take heart from encouragement handed out; I put my heart and soul into it</em></td>
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<tr>
<td></td>
<td>- The central or innermost part of something: <em>right in the heart of the city</em></td>
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<td>- The vital part or essence: <em>the heart of the matter</em></td>
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<td></td>
<td>- Of the type that one understands best: <em>after one’s own heart</em></td>
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<td>- In one’s real nature: <em>at heart</em></td>
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<tr>
<td></td>
<td>- Of deep interest and concern: <em>close to one’s heart</em></td>
</tr>
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<td></td>
<td>- Overwhelm someone with sadness: <em>break someone’s heart</em></td>
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<td></td>
<td>- Of deep interest and concern to one: <em>close to one’s heart</em></td>
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<td>- With sincere feeling: <em>from the bottom of one’s heart</em></td>
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<td>- To be merciful: <em>have a heart</em></td>
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<td>- To be committed: <em>have one’s heart in</em></td>
</tr>
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<td></td>
<td>- To be greatly alarmed: <em>have one’s heart in one’s mouth</em></td>
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<td>- In one’s innermost feelings: <em>in one’s heart of hearts</em></td>
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<td></td>
<td>- Make one’s feelings apparent: <em>wear one’s heart on one’s sleeve</em></td>
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<td>- Sincerely, completely: <em>with all one’s heart</em></td>
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Throughout time classic/contemporary art, film, literature, poetry, and socio-cultural rituals continue to perpetuate our affinity with the symbolisation and significance of a person’s heart. Philosophers, such as van Manen (1990), Heidegger (1962), and Merleau-Ponty (1962), ascribe a vital role to poetising existential, phenomenological exploration and understanding of human phenomena. These philosophers especially relate art, poetry, and literature to the unveiling of what it means to be human. The Liminal Body, as art and reality, speaks to our sensibilities, imprints meaning that can be seen, felt, and understood in indelible ways where ordinary language fails. By appealing to socio-cultural sensibilities, Kockelmans (1987, p. ix) wrote of poetry:

> Often an appeal to poetry and literature is almost unavoidable in that poetic language with its use of symbolism is able to refer beyond the realm of what can be said clearly and distinctly. In other words in human reality there are certain phenomena which reach so deeply into a man’s [person’s] life and the world in which he [she] lives that poetic language is the only adequate way through which to point to and to make present a meaning which we are unable to express clearly in any other way.
Linking to the phenomenon through personal concern

Together with socio-cultural knowledge I consider my own personal experience in relation to the heart. Suddenly, at age sixteen years, while interacting with peers, my heart began contorting within my chest like it needed to escape. As a concept in relation to the arrhythmic heart, ‘suddenly’ is one of the most primordial facets of this human phenomenon.

The living heartbeat is seemingly insignificant, yet has the potential to become mortally significant. In curiosity my friend placed her hand on my chest and immediately recoiled. We never spoke about this phenomenon that neither of us understood. While I have never forgotten this teenage episode, or the look of horror in my friend’s eyes, I did not allow a congenital arrhythmia to prevent me from living life the way I chose. However, approximately a decade ago, the arrhythmia made its presence known again to me and to my life-world. Subsequently, I agreed to have electrophysiology studies (EPS) and cardiac ablation carried out.

Cardiac ablation entails mapping the electrical pathways of cardiac conduction. When arrhythmias are detected the cardiac pathway is ablated with radio waves. After a six hour procedure, which is unpleasant in the extreme, and with my family fatigued and distressed, the cardiologist declared, “She will make me famous.” My concern for and interest in bioelectronics was to have new meaning as I witnessed a lack of empathy and understanding in a health professional in relation to the traumatic effects of cardiac biotechnology. I have since heard these exact words from a colleague involved in a similar encounter, while interacting with a different cardiologist in a different country. Hence, my interest continued to grow.

While I do not have a bioelectronic device, a member of my extended family was a recipient of pacemakers over a fifteen-year period. I was never aware of any complaints or problems he may have experienced, only that he was totally dependent on the pacemaker for life-sustaining cardiac function. His death in 2002 was the result of a failed device through battery depletion while he slept. Such a situation begs the question: How do recipients of bioelectronic devices, such as pacemakers and ICDs,
view their mortality from day to day? How do recipients experience the phenomenon of implantation with a bioelectronic device?

**Linking to the phenomenon from professional concern**

Conversations I have had with many people, cardiac patients, family members, and cardiac nurses, continued to stir my interest in the concepts of non-understanding and misunderstanding within cardiology. Patients admitted for cardiac pacemaker and ICD procedures appear to be especially transient because of their short stay category within the hospital system. In my experience as a cardiac nurse, a twenty-four hour admission, which includes the viewing of a patient education video in relation to ICD biotechnology, is the likely to be all that is offered to sustain a patient through this life-threatening time.

I reflect on one particular night shift when I listened to the concern and fear of a patient who had not consented to any cardiac procedure, yet the cardiologist had informed her that she was listed in his allocated theatre hours the next day. In their apprehension, her family expected her to do “what the doctor wants.” This patient wanted time to decide for herself, and she did. She went home. The situation could have been less stressful for her if it has been managed with understanding and in collaboration. Consequently, my observation is that the notion of taking the time to understand what these patients live through, from the moment of diagnosis with a life-threatening cardiac illness or sudden cardiac death episode, is not always understood or given high priority with health professionals. Seemingly, a true understanding of the phenomenon of implantation with a bioelectronic device is only going to emerge by hearing the perspectives of all those involved.

In Australia, over the past few years, there has been a class action in progress. A group of one thousand Australian recipients of pacemakers discovered, some accidentally, that the model of pacemaker they had within their body and heart “had a potentially deadly flaw” (Nailon, 2000). The manufacturer and distributor organised a recall of the faulty pacemakers but “did nothing to contact the patients directly.” Three patients who were not informed of their situation went public to state how their lives were altered by implantation of their body with faulty pacemakers. One patient believed she was
fortunate to be alive when she suffered a severe seizure while driving and side-swiped a truck. The “violent” seizures continued until this patient broke her leg during a seizure. Investigation of the uncharacteristic seizures resulted in identifying that the pacemaker had intermittently ceased to function.

Another patient expressed his anger at not being informed of the faulty pacemaker. He believed he had been living with a “time bomb, really. Ready to go off.” A prominent cardiologist’s response to the time bomb metaphor was that the danger was more like a “penny banger.” When the third patient became ill unexpectedly, a friend warned her of the faulty pacemakers. This patient’s perspective on cardiac devices was explicit: “Before you implant these devices in human beings, get it right! It is not fair that you put anyone through what myself and other patients have been through” (Nailon, 2000).

I was already involved in a study of the body and bioelectronic pacemakers when the above class action began.

**Linking to the phenomenon as a cardiac researcher**

It was this interest in the person and his/her body experience with biotechnology that led me to question in a previous study, how a person experiences his/her body in relation to invasive cardiac technology (Anderson, 2000). Invasive means, involving the introduction of instruments or other objects into the body or body cavities (Pearsall & Hanks, 2001). It is my belief that there is a fundamental perception that people would prefer not to have invasive cardiac devices within their bodies.

I practiced as a cardiac nurse with cardiac physicians who were highly interventionist and who included in their therapeutic repertoire many invasive procedures aimed at curing or palliating cardiac disease. In my interactions with cardiac patients who were scheduled for cardiac procedures I learned that these patients did indeed regard cardiac technology as invasive. Every day, people had cardiac procedures involving invasion of their bodies, and specifically their hearts. The number of bioelectronic devices implanted, such as pacemakers and ICDs, appeared to be an increasing proportion of the procedures performed. Thus, I undertook an interpretive study of eight recipients of cardiac pacemakers. These recipients had been cardiac patients at the medium sized Australian hospital where I practiced.
The findings of this previous study revealed that recipients’ body experience of bioelectronics was one of varying degrees of ambivalence, inner conflict, powerlessness and suffering (Anderson, 2003; Anderson, McAllister & Moyle, 2002; Anderson, Moyle & McAllister, 2002). On evaluation by recipients of cardiac pacemakers, the Australian publicly-funded program of cardiac intervention fell short of fully benefiting the people for whom the program was designed (Anderson, 2003). In view of this evaluation I reasoned that there was a lack of understanding of the phenomenon of heart implantation from the personal perspectives of the key players.

Having already investigated the body experience in relation to cardiac pacemakers I turned my attention to ICD recipients. I read patient education literature on ICDs and wondered how, or if, the person embodied this bioelectronic device after minimum contact time with cardiac nurses. Some months passed before I realised I was mistaken in thinking of embodiment or disembodiment as the starting point of this study. The starting point of what I wanted to explore, through body perspectives, was the phenomenon that is heart implantation with an ICD.

**Managing the phenomenon of concern**

The task of exploring this phenomenon necessitated looking to the essence of heart implantation. I took direction from Merleau-Ponty (1962, p. vii) in that I could not “expect to arrive at an understanding of [people] and the world from any starting point other than that of their facticity.” Facticity is that concrete lived experience which gives direct description of the lived world as it is (Merleau-Ponty, 1962). van Manen (1990) advocates looking everywhere in the life-world for sources of lived-experience that, when explored, will add something fundamental to the nature of the phenomenon being studied. If a polyphonic inquiry can be managed, a deeper understanding is possible together with a more eclectic study.

The life-world of recipients of ICDs was imperative to this study, because it is these people who are the epitome of the phenomenon of heart implantation with an ICD. While my personal experience placed me in a position of genuine empathy, I have no personal knowledge from the recipient’s perspective. My professional experience
added to my concern for recipients and extended to include the often-overlooked family member’s perspective. Many times, while on night shift, I interacted with family members who attempted to sleep in recliner chairs next to their loved ones, and I appreciated their situation as coming from a different life-world. I needed to include family members in this study.

As a cardiac nurse I work closely with many other cardiac nurses. These nurses may have many perspectives about implantation. Whatever our perspective may be as nurses our task is the same; rendering quality care to our patients. Recipients and family members come into contact with three different groups of cardiac nurses over a twenty-four hour period. Thus, the cardiac nurse’s life-world too, was included.

My own interactions with cardiologists and my observations of their important, though limited interaction with recipients, family members and other cardiac nurses, convinced me to include cardiologists’ life-world. Moreover, it is the cardiologist who initiates and performs implantation of a person’s heart with an ICD. It became apparent that the four unique perspectives of recipients, family members, cardiac nurses and cardiologists, are interconnected in the phenomenon that is heart implantation. Thus, I chose to include in this study the varied perspectives of people from these groups.

**What is implantation?**

The cardiac literature claims the concept of implantation as a scientific term in an overwhelming volume of bioelectronic related material. In an antithetical twist the word implantation has qualitative origins. Another term for implantation is nidation, which originates from the Latin nidus, meaning nest (Pearsall & Hanks, 2001). By reflecting on the connotations of nest, such as home, retreat, or perhaps invisibility, it is questionable whether science has inadvertently misappropriated the concept of implantation. Various other terms, considered by science, included “internal, indwelling, embeddable, intracorporeal, and implantable” (Larsson et al., 2003, p. 116). Perhaps the strong reference to heart arrhythmia in Jules Michelet’s essence of a bird’s nest, cited in a phenomenology of nests by philosopher Gaston Bachelard (1994, p. 101), influenced science to choose the term implantation.
The house [nest] is a bird’s very person; it is its form and its most immediate effort (…) pressed on countless times by the bird’s breast, its heart, surely with difficulty in breathing, perhaps even, with palpitations.

After such reflection I am compelled to ask what has not been asked in relation to the human heart and ICDs, prior to this study: “What is implantation?”

**THE CONTENT OF FURTHER CHAPTERS IN THIS THESIS**

Having shared my ontological world with the reader, it is fitting at this point to expand the direction of this thesis. In this way I hope to engage the reader in a detailed dialogue of exploration and interpretation. In keeping with interpretations of any dialogue it is appropriate to acknowledge that my interpretation of the phenomenon in this thesis is but one of many possible interpretations.

Chapter two is a critical and philosophical review of the known literature dealing with ICDs. The review is organised in a progressive mapping of the history of ICDs and the subsequent evidence-based application of implantation of the human heart with this bioelectronic device into the 21st century. Deficits in knowledge substantiate the research question and support the chosen methodology.

Chapter three offers a detailed examination of Merleau-Ponty’s (1962) hermeneutic phenomenology and existential framework, and explains the way in which this philosophy has provided a theoretical underpinning for this thesis. I guide the reader along an audit trail that explicates methods consistent with a phenomenological research process.

Chapters four, five, six, and seven, will provide analysis and interpretation of dialogue emanating from recipients of heart implantation with an ICD, family members, cardiac nurses and paramedical personnel, cardiologists, and myself. Existential themes are enriched with phenomenological sources to deepen understanding of the research phenomenon: What is implantation? Verbatim excerpts from dialogue assist in a singular understanding. However, a deeper understanding of implantation is only possible through interacting with the dialogue text as a whole experience.
The final chapter encapsulates significant concepts that emanate from the text. Moreover, a universal thread will draw the existential themes together in such a way as to create a more eclectic understanding of the phenomenon of heart implantation with a bioelectronic ICD.
CHAPTER TWO

LOOKING FROM THE KNOWN TO THE UNKNOWN

INTRODUCTION

The aim of this chapter is to examine what is known about the phenomenon of implantation of a person’s heart and body with a bioelectronic implantable cardioverter defibrillator (ICD), by critically reviewing the existing literature. The difficulty with uncovering what is known about this phenomenon is the unmanageable volume of laboratory-based research and clinical trials literature that exists alongside other literature that pertains to the lived experience of the phenomenon. There is a need, however, to understand how the biotechnology of heart implantation with an ICD has evolved and the potential for further evolution into the 21st century.

The ICD has evolved from a bioelectronic treatment of last resort to the ‘gold standard’ therapy for people at risk of sudden cardiac death and life-threatening arrhythmias (Glikson & Friedman, 2001; Lee et al., 2003). This bioelectronics strategy is highly regarded by science and medicine because of its innovative and effective ability, in most cases, to reliably revert cardiac arrhythmias by detecting and providing early defibrillation of the arrhythmic heart (Lee et al., 2003).

In the Australian context, the first person received an ICD in 1988 (Mond & Whitlock, 2001). In the last fifteen years the number of recipients of ICDs in Australia has grown significantly. In 1993 Australia and New Zealand joined a worldwide survey on cardiac pacing and ICD involvement that is collated every four years and submitted to the World Symposium on Cardiac Pacing and Electrophysiology (Mond & Whitlock, 2001). Cardiologist Harry Mond (Mond, 2003) compiled a table that details the number of new ICDs provided by cardiac device companies to institutions participating in heart implantation with an ICD (Appendix B). The last survey results collated for the year 2001 shows 72 ICDs implanted, per million of population for Australia and New Zealand combined. This represents an increase of 125% in new ICD recipients by
comparison to the previous survey for the year 1997 (Mond, 2003). Furthermore, the number of institutions providing permanent ICD therapy for recipients has more than doubled in Australia. A continuance of this trend will account for predicted increases in ICD recipient numbers during the survey scheduled for 2005.

The USA is home base for the engineering and manufacturing companies of cardiac bioelectronic devices such as ICDs, for example Medtronic and Guidant. The American Medicare program in June 2003 reportedly approved cover for double the number of patients who received ICDs in 2002 (Brown, 2003). This increase remains short of the anticipated number (in excess of 300,000 people) that cardiologists and bioelectronic companies believe will suffer sudden cardiac death during 2003. Approved cover for increased heart implantation with ICDs was based on “well-designed clinical trials that add to the body of evidence-based medicine” (Brown, 2003).

Wherever possible in this review, the research on pacemakers and ICDs will be separated. Because of the prolific number of laboratory based studies and clinical trials on electronic pacing and defibrillation of the human heart, only a selection of multi-centre clinical trials will be examined. These clinical trials were chosen because they were instrumental in providing support for ICDs becoming both a primary and secondary mode of treatment for sudden cardiac death (SCD) and life-threatening cardiac arrhythmias. In addition, research that explores and outlines hazards in relation to heart implantation will be critically analysed. Following a brief history of cardiac pacing and defibrillation, a review of recent ICD literature will be presented as appropriate to the scope of this study.

A BRIEF HISTORY OF PACING THE HEART

The intense activity of bioelectronics in cardiology over the past half century has been compared to the systolic phase of the cardiac cycle (Braunwald, 1991). In other words, there has been no resting phase in bioelectronic pacing innovation. Although the effects of electro-stimulation of muscle tissue was known early in the eighteenth century, pacing the heart required the imagination and innovation of scientists, such as Paul Zoll (1952) and Wilson Greatbatch (1991), to inspire this intense activity.
Paul Zoll’s imagination stirred as he stimulated the exposed hearts of soldiers with the blade of a penknife on the battlefield in World War II (Anonymous, 1999). Eventually, Paul Zoll’s work with external pacemakers was recognised with America’s highest award for research. Greatbatch’s engineering innovation led to his hand-made pacemakers being the first successful human heart implantations performed by American thoracic surgeon, William Chardack in 1960 (Chardack, Gage & Greatbatch, 1960).

A Swedish cardiologist, Ake Senning, attempted the first human heart implant in 1958, but the device failed after three hours (Senning, 1983). Subsequently, Ake Senning successfully implanted a pacemaker in 1960 and his male recipient, who was alive in 1998, received a further 26 pacemakers over this 38-year period. Eventually, permanent cardiac pacemakers gained approval from the Food and Drug Administration (FDA) in 1985. Twenty years after the cardiac implantation success of Paul Zoll, Ake Senning, and Wilson Greatbatch, the number of pacemaker recipients had risen to half a million worldwide (Jeffrey & Parsonnet, 1998).

From a humanistic perspective, Wilson Greatbatch (1991) stated that the highest quality military electronics was inadequate to conquer the internal environment of the human body. Furthermore, success in invading the body proved more difficult than invading outer space. While an industry was evolving around cardiac pacing for bradyarrhythmias and complete heart block, the issue of sudden cardiac death and tachyarrhythmias remained treatable only as an in-hospital cardiac event.

**One man’s vision**

During the excitement within the scientific world that realised cardiac pacing, a young doctor in Israel, Michel Mirowski, struggled with the loss of a close colleague who had suffered repeated life-threatening cardiac tachyarrhythmia (Wolf, 1998). As a result, Michel Mirowski’s vision was to implant the body with the necessary electrical force to defibrillate the heart and restore normal function. Michel Mirowski emigrated from Israel to the USA where he developed a prototype of a miniature defibrillator that could be implanted within the human body. Mirowski hypothesised that 20 joules of
electricity could revert life-threatening arrhythmias when the device leads had direct contact with the heart (Wolf, 1998).

During open-chest surgery in 1947 the first successful defibrillation of the human heart was reported (Medtronic, 2003). Michel Mirowski was developing his prototype in the late 1960s, however the first successful human implantation with an ICD took place in 1980 at John Hopkins Hospital (Mirowski et al, 1980). The early devices required open-chest surgery because the device leads needed to connect directly to the outer surface of the heart. In 1993 a lead system that could be manoeuvred through a vein and attached to the inner wall of the heart was released, negating the need for open-chest surgery (Medtronic, 2003). More sophisticated biotechnological advances followed.

**State of the art biotechnology**

Current ICDs are capable of cardiac pacing therapy, synchronised cardioversion or cardiac defibrillation. In addition, it is common for pacemaker-dependent recipients to be additionally implanted with an ICD. Dual implantation allows for atrium and ventricle pacing capability with reduced battery drain. However, the ultimate in ICD technology provides dual-chamber pacing, which precludes the need for separate pacemakers and ICDs (Bailin et al, 2003).

The modern ICD is a microcomputer with set therapy parameters for optimum detection of arrhythmia and discrimination capability for the level of electrical therapy required. The accuracy of the device can be checked via the electrocardiographic tracing record that is stored in memory at the time of arrhythmia detection. Magnetic radio waves within a wand device interrogate the ICD during recipient check-up and this information is relayed to the device programmer. Analysis of the stored information determines whether new parameters need to be set (Altemose & Groh, 1999).

**Biotechnology for implanting the heart**

Pacemakers and ICDs are designed using the principles of engineering and biocompatibility (Wagner, 1995). The specific components of the implantable cardiac
device include the battery within a pulse generator and the leads (Appendix A). The unit’s function is to provide the cardiac muscle with electrical stimuli to maintain the heartbeat within predetermined parameters. These parameters act as a guide to sensing, pacing, recording, and defibrillating the heart. The unit is described as the size of a matchbox (5 cms). The shape of the ICD protrudes from the site of insertion. Early models required abdominal wall implantation while today’s units are inserted into a tissue pocket below the clavicle. Titanium, as the coating of choice for the unit is a hard, silver-grey metal. It is strong, light, and corrosive-resistant. A metal capsule is required for the ICD unit to prevent body fluid penetration and to withstand sterilisation (Wagner, 1995).

The device leads, which carry the electronic activity from the battery to the defibrillating electrode, are coated in either polyurethane (plastic) or silicone rubber and manoeuvred into the endocardium (interior heart) through the superior vena cava via the cephalic vein or subclavian vein (Wagner, 1995). Once in place the electrodes at the end of the leads are fixed into position by styli penetration of the heart-wall. Body chemistry recognises the foreign material immediately the device is implanted within the body, an immune response is triggered and the rejection mechanism of inflammation begins (Wagner, 1995). Consequently, debate still surrounds the advantages and disadvantages of different lead insulation (Cameron et al., 1990; Pavia & Wilkoff, 2001). The electrode tip is usually fixed by stylet against the inner layer of cardiac muscle and becomes targeted by foreign body giant-cells, which attempt to form a barrier between the electrode and the cardiac muscle. During this mechanism the electrode becomes encapsulated (Wagner, 1995). This is the body’s attempt to protect itself from the foreign object. Thus, suppression of the body’s natural defences becomes the only chance for a successful implant, and to this end, “behind the porous tip surface is a silicone rubber plug filled with an inflammation suppressing steroid” (Mond et al., 1988, p. 215).

The pulse generator controls the use of the charge stored in the battery, which is a matter of supply and demand. As the encapsulation of the electrode tip builds up over time, changes in the geometrical shape of the tip develop and the electrical stimuli on the heart muscle decreases. Hence, the generator demands more charge from the battery, which eventually causes battery depletion (Wagner, 1995). Within the body,
ICD batteries seldom perform for the recommended six-year period (Kanagaratnam et al., 2002). Modern batteries contain lithium and iodine to prevent a gaseous reaction and to withstand body fluids (Mond & Stokes, 1991). Overall, there are no known “entirely” biocompatible materials that can be used for bioelectronic devices (Wagner, 1995, p. 154). Hence, no advances in coating materials for these devices have been reported (Medtronic, 2003).

Reflecting on an established alliance between cardiology and the cardiac device industry, Harthorne (1985, p. 957) predicted, “implantable computers that will serve as an electronic service centre” would precipitate an expanding market in cardiac electronic stimulation. Harthorne’s prediction in 1985 has been realised. Global sales of predominantly implantable cardiac devices, including ICDs, were valued at $7.7 billion for the fiscal year ending April 2003 (Collins, 2003). As Werner (1998, p. 1) suggested, “the business of producing, marketing and selling pacemakers and ICDs is at once the most technologically and financially exciting and rewarding segment in the entire industry” of body implantation.

**Global developments in ICD bioelectronics**

Major American cardiology specialist organisations, such as NASPE (North American Society of Pacing and Electrophysiology), TCT (Transcatheter Cardiovascular Therapeutics), and the American Heart Association, routinely attract membership from cardiologists worldwide, along with manufacturers of cardiac devices, including Medtronic (Werner, 1998). A close association exists between these organisations because of the extensive research and development that sustains the cardiac pacing industry. Medtronic claims to be the world’s leading medical biotechnology company (Medtronic, 2003). The company contends that every seven seconds a person’s life is improved by a Medtronic cardiac product or therapy, such as ICDs. Medtronic, one of several global cardiac product companies, operates in 120 countries worldwide, including Australia. The company slogan reads: When Life Depends on Medical Technology. If the message put out by companies, such as Medtronic, is accurate and life depends on ICD bioelectronics, for some people, health professionals require that evidence of the effectiveness of the biotechnology be unequivocal.
PRE-UNDERSTANDING IN THE LITERATURE

A search of CINAHL and Medline databases in June 2003 yielded a prolific number of papers on ICDs. These papers do not account for all the highly technical research papers on ICDs that are published in specialty journals, such as Pacing and Clinical Electrophysiology. However, basic research, applied research, and clinical research, in the field of cardio-bioelectronics are not the focus of this review. These types of research do not explore how this biotechnology is experienced in the lived-world. I chose to focus on the most recent known research having a humanistic application that will reveal the gap this study seeks to address. Before this is undertaken, however, I will briefly outline the major research studies conducted to explore the efficacy of ICDs as a treatment for sudden cardiac death (SCD) and life-threatening arrhythmias.

A brief overview of recent research conducted into the effectiveness of ICDs

Numerous major multi-centre clinical trials were conducted during the last decade. The results of these randomised clinical trials (RCT) vary in their estimation of the effectiveness of ICD therapy in decreasing mortality compared to the use of antiarrhythmia medication. A recent systematic review with meta-analysis was conducted of eight RCTs (Ezekowitz et al., 2003). Ezekowitz’s group rejected many [377 of 385] reports on the efficacy of ICD therapy versus antiarrhythmia medication. This indicates that while there are numerous studies, few are rigorous RCTs when comparing ICD therapy with medication therapy in selected cardiac populations. After searching all relevant databases, registries, and consulting with ICD experts, validity assessment and data abstraction authenticated eight trials. The eight trials in the final analysis had an aggregate of 4909 patients and included all-cause mortality in 1154 patients. Ezekowitz et al., (2003) concluded that ICDs prevent SCD regardless of underlying risk. However, conclusions were conservative in view of ICD impact on total mortality being patient-case sensitive.

An earlier meta-analysis of studies, conducted by a European Working Group, recommended that implantation be modified to include individual circumstances (Hauer et al., 2001). The group acknowledged ICD benefits and unfavourable outcomes.
Unfavourable outcomes included patient-related problems that needed addressing in future research.

- Absence of cure and the feeling of being device dependent.
- Implantation hazards and replacement hazards associated with a certain rate of complications.
- Frequent shock delivery in patients with many arrhythmia recurrences.
- Limitations on fitness to drive.
- Psychiatric disorders may interfere seriously with acceptance of ICD therapy. (Hauer et al., 2001, p. 171).

While saving lives through establishing the efficacy of the most effective therapy is important, essentially these studies present a struggle for dominance between two technologies: ICD therapy and medication therapy. The earlier trials, such as the Canadian Implantable Defibrillator Study (CIDS) and the Cardiac Arrest Study Hamburg (CASH), failed to establish a statistically significant difference in outcome for patients receiving ICD therapy compared to those patients receiving antiarrhythmia medication (Kuck et al., 2000; Sheldon et al., 2000). One arm of the Coronary Artery Bypass Graft Patch Trial (CABG Patch Trial) explored the effectiveness of ICD therapy in reducing mortality in high-risk post-surgical patients and found no improvement in survival (Bigger et al., 1999). It is only in the better-controlled trials, focused on patients with inducible ventricular tachycardia, such as the Antiarrhythmics Versus Implantable Defibrillators (AVID) and the Multicenter Automatic Defibrillator Implantation Trial (MADIT) that the efficacy of ICD therapy over medication has been established (Moss et al., 1996; Steinberg et al., 2001).

The results of the clinical trials, especially the Multicenter Automatic Defibrillator Implantation Trial (MADIT) (Moss et al., 1996), have been instrumental in transforming the ICD to a first-line intervention for SCD and life-threatening arrhythmias. Moreover, antiarrhythmia drug technology, as a competing therapy with ICDs, has not lost efficacy as a result of ICD therapy appearing superior. As Page (2000) concluded, most patients require a combination of both therapies for optimum management.

Heart implantation with an ICD in tandem with antiarrhythmia medication has been well established as a treatment by clinical trials, and well accepted by cardiology and most healthcare consumers (Higgins, 1999). However, studies have continued to report
technological problems with ICDs and side effects with antiarrhythmia medication (Owens, 1997). Empirical research is valuable in establishing the effectiveness and efficiency of ICD therapy, but the impact-cost on peoples’ lives from personal perspective is under-researched. Moreover, the humanistic voice that presents the experience of implantation with an ICD has remained relatively silent. As previously stated, these multi-centre clinical trials have been the benchmark for America’s Medicare program substantially increasing approval for ICD therapy. However, these clinical trials represent the empirical perspective. Thus, a significant gap exists in experiential research from a human-science perspective. This study will contribute to addressing such a gap by engaging in a humanistic approach.

Technological complications

Strict criteria, drawn up by the American Food and Drug Administration (FDA), classified ICD technology problems as complications (Glikson & Friedman, 2001). Identified ICD complications in multi-centre clinical trials propelled the defibrillator industry to be more innovative in ICD essential functions, such as arrhythmia detection, arrhythmia treatment, bradycardia pacing, and episode-data storage (Bardy et al., 1996). To be manageable, the most common complications with ICD bioelectronics were chosen for discussion in this summary, these include: lead dislodgement and failure (Brady et al., 1998; Mera et al., 1999), device failure and malfunction (Miller & Hsia, 1996; Wood, Ellenbogen & Liebovitch, 1999), electronic interference (Fetter et al., 1998; Groh et al., 1998; 1999; Harthorne, 1999; McIvor et al., 1998; Occhetta et al., 1999; Santucci et al., 1998), pocket infection (Grimm et al., 1999; Link et al., 1999), inappropriate shocks (Brugada, 1999; Weber et al., 1999), diaphragmatic stimulation (Block, 1995), and venous stenosis (Friedman et al., 1999).

Scientists and cardiologists undertook studies into these complications, and many more similar projects, in order to meet the guidelines for medical device use set down by the FDA (2000). Australian Medical Devices Guidelines as set out by the Therapeutic Goods Administration (TGA 2002, p. 5) require medical devices “to have undergone a clinical evaluation by the manufacturer.” ICD manufacturers are USA-based, therefore the FDA guidelines are a more comprehensive document than the Australian Medical Devices Guidelines.
The FDA (2000, p. 6) defines complications in the use of ICDs as hazards:

A hazard is a potential source of harm. Hazards arise in the use of medical devices due to the inherent risk of medical treatment, from device failure (or malfunctions), and from device use. Hazards resulting from medical devices impact patients, family members, and professional healthcare providers.

Thus, the technological complications or the hazards of the ICD mentioned in the above studies remain an inherent risk of this medical treatment and impact patients, family members, and healthcare providers. A study exploring the experiential impact on all these groups has not been undertaken and remains a gap amidst a vast number of studies on the technical aspects of ICDs.

The remainder of this review deals with significant recent research material that substantiates the impact of ICD hazards on the human heart, the impact on the many facets of psychosocial well-being, and the impact on quality-of-life involving patients and family members.

**Heart implantation as body-hazard**

By its very nature as a bioelectronic device, the ICD can present as a body-hazard. Some of the main hazards that add to the life-threatening morbidity of needing heart implantation of an ICD, include: lead failure and difficulty with unused or malfunctioning leads within the body, such as those visible in The Liminal Body photograph; infection; the paradox of ICD therapy, whereby there is too little or too much therapy; and ICD recall because of faulty devices.

Heart implantation with an ICD has become the accepted therapy for patients with life-threatening arrhythmias, regardless of underlying morbidity. With the growing application of ICD therapy, concern about the long-term reliability of ICD leads is increasing (Gradaus, Breithardt & Bocker, 2003; Hauser et al., 2003). Lead failures in ICDs as a body-hazard, have prompted many studies to unravel the complexities of lead failures and these hazards continue to challenge modern bioelectronics (Bracke, Meijer & Van Gelder, 2003; Weretka et al., 2003). Ellenbogen et al., (2003) systematically followed lead function in 74 patients with ICDs over a five-year period. During the
five-year follow-up period fifteen patients underwent lead extraction and replacement; two patients had ICD leads capped and new leads implanted; one patient required a new sensing lead; and one patient required a new ICD system. The body-hazards encountered by these patients included over-sensing of the ICD resulting in inappropriate and sustained shock therapy; under-sensing of arrhythmia; and infection. While identification of ICD lead malfunction is imperative for the continued well-being of patients, Ellenbogen et al., (2003) described the hazard as a scientific Achilles heel. The study neglects to extend this Achilles heel metaphor to the human being who could lose his/her life or quality-of-life.

The extraction of chronic indwelling ICD leads is a non-trivial event (Cooper et al., 2003b) because scar tissue forms after implantation and progresses over time, especially under high-energy shock therapy. Cooper reported retrospectively on fourteen young, active ICD recipients who required extraction procedures to remove twenty-one malfunctioning leads in young recipients. Lead adherence causing altered anatomy is a result of the large size of ICD leads. In these cases lead extraction is vital if accumulation of implanted hardware is to be avoided (Cooper et al., 2003b). From a humanistic perspective altered anatomy potentially leads to altered body-image. However, the scientific perspective in Cooper’s work focused on the substantial cost to the bioelectronic industry.

A literature review on ICD lead malfunction and extraction (Bracke, Meijer & van Gelder, 2002) concluded that the follow-up period of two years, used in eleven studies, is inadequate due to lead malfunction increasing over time. This study also presented lead malfunction as predominantly resulting from infection and “twiddler’s syndrome.” Bayliss coined the term ‘twiddler’s syndrome’ in relation to cardiac pacing leads in 1968 (Bayliss et al., 1968, p. 1). Twiddler is a pejorative label that essentially blames the person for either consciously or unconsciously interfering with the implanted ICD (DeBuitleir & Canver, 1996). Patient blaming could be being used as a tool to decrease scientific responsibility in order to meet FDA guidelines on ICD hazards.

A contrasting attribution of cause was presented by Stephen Pavia, Director of Cardiac Pacing and Tachyarrhythmia Devices, The Cleveland Clinic Foundation, who chose to classify lead malfunction and other ICD hazards (Appendix C) as complications arising
from lack of meticulous implantation (Pavia & Wilkoff, 2001). These authors, in a meta-analysis of hazards associated with implantable cardiac arrhythmia devices, described the risk of developing complications as “significant and enormous” (Pavia & Wilkoff, 2001, p. 71). In addition, decisions on heart implantation needed to be based on sound guidelines, which would evaluate the efficacy of implantation. Such evaluation could contribute to a decrease in complications, such as infection.

Over recent years the research on ICD hazards has inclined towards all-cause complications with heart implantation, even though post-implantation infection contributes to significant mortality (Kuhlkamp et al., 2003; Takahashi et al., 2002; Wasson et al., 2003). The authors of these research studies contended that the lack of research into ICD infection, post-implantation, was a limiting factor in prevention-research on nosocomial cardiac infections. Regardless of antibiotic treatment being part of standard protocol, GiamarelloLou (2002) ascertained that infection rates in ICDs approximate pacemaker infection rates and are as high as 50%.

Studies focusing on implantation infection stated that explantation of the ICD system was unavoidable if patient survival was to be achieved (Kron et al., 2001; Mela et al., 2001). In addition, risk of acute and chronic infection exists at multiple sites from numerous hazards. The Kron et al., (2001) study treated 78% of 539 ICD recipients with preoperative, intraoperative, and postoperative antibiotics. Even though infection still occurred in fourteen recipients, the necessity for antibiotic protection was supported by the incidence of infection in two thirds of recipients not receiving antibiotic treatment. However, the statistical reporting of these studies overlooks the cost in human terms for patients whose lives constantly remain in limbo because of life-threatening cardiac arrhythmias, potential SCD, and life-threatening ICD-effect body-hazards, such as the potential for infection.

The phenomenon of heart implantation with a permanent ICD is neither a cure for nor a guarantee against SCD, despite the plethora of studies that advocate the efficacy of ICD therapy (Pires et al., 2002; Stevenson & Epstein, 2003). Mitchell et al., (2002) reported that optimal ICD use did not prevent cardiac death in 78% of 320 patients who died while being treated with ICD therapy. In Mitchell’s study the ICD parameters failed to detect malignant VT/VF and/or further failed to prevent cardiac death after delivery of
full ICD therapy (full therapy includes four to six electromechanical shocks). Furthermore, cardiac death occurred in patients whose normal rhythm was restored by ICD therapy. Ironically, appropriate ICD function can replace malignant arrhythmias with shock-induced electromechanical dissociation which Mitchell et al., (2002) termed, ‘cardiac annihilation.’ This confusion of recognition between the bioelectronic ICD and the human heart was described as a phenomenon, a qualitative descriptor, which is rarely acknowledged in scientific research.

Multiple sequential ICD shocks to a person’s heart is referred to as an electrical storm, and is regarded as an ominous predictor of mortality (Adler et al., 2001; Greene et al., 2000; Korte et al., 2000). In one study, electrical storm consisting of 55-91 shocks per storm, experienced by forty patients, was described as an “exclamation mark” and as yet another “unpredictable phenomenon” in heart implantation with an ICD (Greene et al., 2000, p. 268). While this study was relatively small, Korte et al., (2000) studied 180 patients who required hospital readmission within the first year post-implantation with an ICD because of multiple appropriate shocks. Korte concluded that further investigation of prevention-strategies for electrical storm was needed in modern ICD therapy. Adler et al., (2001) reached a similar conclusion after investigating a larger group of 537 patients who experienced a total of 3500 shock therapies during first year post-implantation. In contrast, two recent studies with similar patient numbers, 133 and 155 respectively, found that patients did not suffer significant occurrences of life-threatening arrhythmia in the long-term post-implantation (Gillis et al., 2003; Rinaldi et al., 2003). Thus, prediction of ICD efficacy and ICD interaction with the human heart remains elusive and hazardous; “the marriage of device and patient remains controversial in many populations” (Friedman, Glikson & Stanton, 2000, p. 697). As a phenomenon of such immense complexity, scientific studies continue to demonstrate that statistics and classifications are inadequate when attempting to understand the coupling of bioelectronics and the human heart.

As previously stated the FDA is the regulatory agency that sets guidelines for compliance by ICD manufacturers. The frequency of ICD recall and safety alert is increasing over time as the incidence of heart implantation with ICDs continues to rise (Maisel et al., 2001; Maisel, Stevenson & Epstein, 2003). The most recent weekly FDA Enforcement Report accessed for this study, issued a nationwide recall of 396 ICDs.
One meta-analysis of FDA weekly reports on cardiac pacemaker and ICD recalls or safety alerts spanned the decade 1991 to 2000 (Maisel, Stevenson & Epstein, 2003). The study results revealed a 700-fold increase in circuitry hazard and a 20-fold increase in battery malfunction. These hazards involved more than half a million devices. The results of the original study by Maisel et al., (2001) revealed that in the decade-long study of FDA recalls, ICDs were recalled in eight of those years while implantation rates increased 11-fold. Furthermore, the yearly increase in implantations continued to rise by between 16% and 33%. It was noteworthy that in such an extensive study a mere five lines of acknowledgement were given to the psychological impact on patients.

For this study, the human effect in terms of life-threatening trauma is equally important. Device-recall studies omit this aspect. While FDA presents as an effective quality enforcement agency, there are no studies dealing with the experience of patients with faulty ICDs. The absence of perspective from patients and significant others is a gap in knowledge to which the present study may contribute.

**Heart implantation as psychosocial-hazard**

An expanding area of concern is evident in recent studies that focus on the psychosocial impact of heart implantation with an ICD. Patient reports, although still few in number are beginning to filter through in studies from the USA, Sweden, and Australia. Health professionals are acknowledging negative effects of implantation, such as depression, as a significant biopsychosocial-hazard. Psychological anticipation of pain and fear of painful ICD therapy has been noted by researchers. Hence, recipients in need of support and counselling are discussing these biopsychosocial traumas on the internet.

A meta-analytic review of twenty studies (1989-2000), reporting from valid and reliable measures of psychological functioning in ICD recipients and appropriate comparison groups, found no significant differences between four groups in psychosocial outcomes (Burke et al., 2003). The chosen study literature was analysed to identify difference in psychosocial well-being between four groups:
ICD patients and drug-maintained ventricular arrhythmia (VA) patients (n=649).
ICD patients and other cardiac patients (n=890).
Pre-implantation and post-implantation patients (n=102).
ICD patients who had experienced shock therapy and those who had not experienced shock therapy (n=380).

In relation to significant difference involving psychological or physical functioning, the review revealed no significant difference between ICD patients and medicated patients. Nor was there significant difference between patients pre-implantation and patients post-implantation. The same result was found for patients receiving shocks and those who did not. However, a significant difference was found between ICD patients and other cardiac patients (Burke et al., 2003). There is a vast range of psychological testing measures for categorising psychosocial well-being, anxiety, depression, mood disturbances, and quality-of-life. These tools identify that the person is anxious or depressed but they are not sensitive enough to explore what it means to the individual person to live each day with the unpredictability of heart implantation and electric shock.

Physicians and nurses (n=261 of 1465 contacted) providing care for ICD recipients took part in a national self-report survey consisting of forty nine items assessing their perspectives on specific biopsychosocial concerns of ICD recipients (Sears et al., 2000). Findings concluded that approximately 20% of ICD recipients were perceived by health care providers to be experiencing significant negative effect in relation to physical well-being, emotional function, strained relationships, loss of independence, dealing with ICD shocks, and depression. Furthermore, health care providers reported most comfort dealing with medical issues, such as compliance, and least comfort dealing with depression and anxiety. Phillips (2000) agreed in her dissertation that depression should be considered an important co-morbid issue in life-threatening illness, such as heart implantation with an ICD and that depression warranted regular screening and support intervention. To enable health professionals to be more aware of patient’s psychological well-being and the need for support, more person-focused evidence is required. Such humanistic knowledge can be gained from experiential studies.

A Swedish phenomenographic study outlined a schematic description of conceptions regarding the life-situation of fifteen patients with ICDs using a holistic concept.
The life-situations of biophysical, emotional, intellectual, socio-cultural, and spiritual-existential, included the conceptions; feelings of safety, feelings of gratitude, feelings of being, having a network, having a belief in the future, and gaining awareness (p. 43). The authors suggested that their findings, from 454 statements in nine interviews, did not differ from previous American studies involving recipients of ICDs in terms of life-benefits and life-intrusions, but highlighted the need for support groups and more informed health professionals. The use of phenomenography in Fridlund’s study meant that it fell short of capturing the essence of heart implantation and thus a deeper understanding was not achieved. In addition, family members continue to be denied a voice in the phenomenon of heart implantation with an ICD.

In contrast, two Australian interpretive phenomenology projects have undertaken to include both recipients of ICDs and family members. Three recipients of ICDs and three family members shared their experience of the ICD impact on their lives (Eckert & Jones, 2002). Themes that explicated meaning included: dependence encompassing perceptions about the life-saving device; remembering their first defibrillation experience; lifestyle changes using modification techniques; lack of control highlighting fear, anxiety and powerlessness; mind game illustrating psychological challenges; the security issue of how ‘being there’ and ‘not being there’ impacted on everyday life (p. 152). While this study is smaller than other studies discussed in this review, in phenomenology that is not a problem if saturation is achieved. However, by combining the thematic analysis of the two separate groups the specific perspectives of each group was denied a voice. Undeniably, recipients and family members live everyday life with the psychosocial hazards of the ICD, but each person has a unique experience that may be similar to another, but never the same. The different experience between recipients and family members was captured in the second study.

Seven recipients of abdominally implanted ICDs and six partners participated in an interpretive phenomenological study (Reid, 2001). The study results described four patient themes: being disrupted, reconstructing life, appreciating and celebrating life, and accommodating the technology (p. 138). These themes followed a temporal path of meanings for the person whose life changes to include heart implantation, then moving on because life continues. Four partner’s themes were similar yet different: being
disrupted - the distressing near loss of a loved one; reconstructing life; appreciating and
celebrating life; and accommodating the ICD (p. 185). In keeping with the
methodology, this study provided full scope for the individual voice of each participant
from similar and contrasting perspectives. Nonetheless, with the current advancements
in bioelectronics in ICDs that exist, data on abdominally implanted ICDs are somewhat
dated. A comparative study on abdominal implantation and pectoral implantation
would add significantly to the knowledge base on the psychosocial hazards of heart
implantation with an ICD. Such a gap exists in ICD research and would serve to
highlight biopsychosocial issues experienced in implantation of the heart and body.
Reid’s study outlined a support program, which pointed to the many psychosocial issues
that recipients and family members struggle to cope with on a daily basis.

Support in adjustment management was found to be significant for 40% of 76 recipients
of ICDs (Duru et al., 2001). Recipients’ psychosocial well-being was evaluated using
scales, surveys and questionnaires, such as the Hospital Anxiety and Depression Scale
(HADS). Summary ratings revealed that ICD recipients perceived the ICD as a life
extender. In addition, the device provoked high anxiety about battery depletion,
technical problems, and life limitations. The HADS was also applied in a pilot study of
five ICD recipients hospitalised and presenting with panic disorder, agoraphobia, and
depression (Kuijpers, Honig & Wellens, 2002). After treatment with antidepressants
four of the five patients demonstrated psychological improvement and became
“electrically more stable” (Kuijpers, Honig & Wellens, 2002, p. 183). Conclusions
included a possible relationship between affective disorders and cardiac arrhythmias
leading to frequent ICD shock therapy discharge. Moreover, Kuijper’s pilot study
indicated that major research on the efficacy of short-term antidepressant therapy would
be more supportive in heart implantation with an ICD than being labelled with a
psychological ‘disorder.’ Many psychiatric and psychological scales and measuring
tools exist for psychological diagnoses, however, a cardiac arrhythmia needing ICD
therapy is a holistic experience that appears to have entered the paradigm of dual
diagnosis. As a holistic experience, implantation would be more appropriately
understood from within the paradigm of interpretive studies, such as phenomenology.

Experimental studies have investigated the hypothesis of dual associations in ICD
patients (Pauli et al., 2001; Pauli, Montoya & Martz, 2001; Wiedemann, Pauli &
Dengler, 2001). Dual association refers to the psychological affect observed in patients before the ICD shock therapy was experienced. An anticipatory bias and associated pain with ICD shocks and anxiety was examined in twenty-four patients with ICDs using thought experiment (Pauli et al., 2001). Fear relevance (FR) stimuli in relation to ICD therapy was compared to non-FR stimuli, such as plants. Results showed ICD therapy to be a traumatic experience with high expectancy bias and high anxiety levels.

Blumenthal et al., (2001) investigated pain perception and pain thresholds, in relation to electrical shocks. Electric shocks were delivered to the patient’s arm at 1.5 times the tolerated pain threshold in twenty young adults to determine the pain experience of patients during ICD therapy (Blumenthal et al., 2001). Blumenthal’s study findings claimed that prepulsing before electric shock reduced pain perception associated with ICD therapy. The most recent experimental pain study located for this review, measured sustained sympathetic arousability through the startle reflex paradigm in 134 patients experiencing frequent ICD therapy (Ladwig et al., 2003). Results demonstrated that sympathetic arousability remained high in this patient group. Despite experimental studies involving human pain raising doubts about ethical boundaries, these studies highlight the human dimension of heart implantation and ICD therapy that needs to be given a voice through humanistic approaches, such as phenomenology.

The internet has developed as a technological support mechanism in the lives of ICD recipients. For patients who have no other means of being part of a support group the internet can be a source of information and mutual exchange of biopsychosocial hazard management (Dickerson, Posluszny & Kennedy, 2000). Interpretive phenomenology was used to explore potential benefits for ICD recipients and interested others who accessed a website bulletin board over a fifteen-month period (Dickerson, Flaig & Kennedy, 2000, p. 252-253). Seventy-five respondents contributed 469 postings seeking discussion on biopsychosocial perspectives. Four relational themes and one constitutive pattern were found from the text:

- Seeking and giving meaningful information.
- Sharing personal perspectives.
- Storytelling as common grounding.
- Supportive interacting.
- Constitutive pattern: Therapeutic connection.
Dickerson (2002a) followed the previous study with a similar project using a virtual focus group on a website for twenty-four ICD recipients over a four week period. Seven major meanings were found in patient communication via the internet: a need for knowledge and support; getting past the fear of living with uncertainty; internet as a window to the future; internet as access to people with similar experience; internet as a mountain of information and goldmine of knowledge about ICDs; internet as social interaction; becoming informed consumers of health care (Dickerson 2002a, p. 1). These findings from phenomenological studies demonstrate the need for support in sharing the psychosocial effects that heart implantation with an ICD can invoke in this group of patients. However, over time, Kraut et al., (1998), found that there is the potential to become more isolated from family and friends and more dependent on electronic interaction when using the internet. The inclusion of family members’ perspectives in studies where patients have life-threatening arrhythmias requiring ICD therapy would instil more meaning into the phenomenon of implantation.

Worldwide literature substantiates the fact that cardiac teams involved in heart implantation with an ICD rarely include a mental health professional who can assist recipients and family members with psychosocial issues associated with high levels of anxiety, depression and avoidance tendencies (Eads et al., 2000). A meta-analysis of findings from the psychological literature (1987-1999), dealing with the psychosocial effects of living with an ICD within the body, identified seven principles of supportive communication; problem definition, providing information, creating team support, normalizing fears, eliciting emotional release, instilling hope, and encouragement to take action (Eads et al., 2000, p. 109). This meta-analysis is important and valuable information for health professionals, yet it fails to capture the uniqueness of the experience and meaning of heart implantation.

Implantation requires a humanistic approach to explore experience and to help develop our understanding of the multifaceted, interlocking nature of this complex phenomenon. To do this it is also important to include how health care providers perceive the biopsychosocial impact of the ICD on their patients’ quality of life.
Heart implantation as quality-of-life-hazard

Although there are many studies dealing with quality of life (QOL) issues experienced by recipients of ICDs, Carroll, Hamilton & Kenney (2002) have stated that the current research attention has been more focused on the physiological effects of implantation rather than the holistic effects on human being. Recent studies discussed in this section include: restrictions on driving that are symbolic of loss of independence and control over QOL; life situation post-implantation; sleep deprivation; and QOL from the ICD trial studies, such as CIDS and AVID.

Quality of life is a dynamic construct most often quantified within many different paradigms of QOL instruments (Allison, Locker & Feine, 1997). Moreover, there is the presumption that the point of reference remains stable. In addition, within the complexity of human beings a person’s subjectivity toward life and death situations can invalidate QOL measurement and this has been largely overlooked. Allison et al., (1997) wrote of this phenomenon as response-shift bias. Such different paradigms of QOL are based on changing situations, such as health status, expectations, adaptation, self-control, and self-concept.

Restrictions on driving a vehicle demonstrate the importance of independence for recipients of ICDs and family members. In the USA eight recipients and their partners agreed to semi-structured interviews in an interpretive study that resulted in five themes representing QOL-hazard: feelings of resentment, feelings of anger, increased dependence on others, lacking confidence in driving, and imposed family sanctions when driving (James, Albarran & Tagney, 2001, p. 80). Additional QOL-hazards included altered self-image, loss of independence and social isolation. These findings were consistent with other studies where driving bans impacted on QOL issues such as, dependence on others, relationship conflicts, social isolation, threats to personal identity and personal control (Lewin, Frizelle & Kaye, 2001). In these and other interpretive studies, the use of semi-structured interviews can be limiting because the study questions emanate from the researcher’s frame of reference rather than the person’s individual perspective. The above authors advocated a larger study about resumption of driving for ICD recipients.
Nine months into the Antiarrhythmics Versus Implantable Defibrillators (AVID) trial 802 participants from both arms of the study completed two surveys on driving habits (Hickey et al., 2001). One survey dealt with resumption of driving over time and the second dealt with arrhythmic events during driving. The surveys showed that 58% of participants resumed driving within six months of the initial arrhythmia on the basis of QOL; also that 34% experienced arrhythmic events while driving. Within these percentages there were no significant differences between the ICD arm and the medication arm of the study. These results are valuable in reinforcing the guidelines for driving restraints until cardiac patients stabilize. However, the results also confirm how deeply valued QOL can be when threatened by restraints. The AVID researchers agreed that more valid research was needed in this area. Uncertainty compounds QOL-hazards that exist in the life situation of ICD recipients.

Life situation for fifty-six ICD recipients in the USA was measured using three questionnaires repeatedly administered over a period of twelve months (Flemme et al., 2001). Uncertainty was measured by using the Mishel Uncertainty in Illness Scale (1981); Ferrans and Powers’ (1985) QOL Index measured satisfaction in health functioning, socio-economic, psychological-spiritual, and family; the Patient Implantable Cardioverter Defibrillator Questionnaire (Brodsky et al., 1988) measured insecurity and fear in relation to living with an ICD. The study findings demonstrated an improvement in recipients’ QOL over time on all three measures. Nevertheless, statistical results do not discriminate between aspects of QOL, identifying when a person’s QOL improves in one aspect, but at the same time deteriorating in another aspect. A QOL-hazard, such as agoraphobia (Godemann et al., 2001) or sleep deprivation (Fries et al., 1999) can tend to be overlooked in an overall favourable outcome of the study. Such experiential hazards are most appropriately captured in an interpretive study that offers people a voice.

Fichter et al., (2002) recognized the need for a study on sleep-related breathing disorders. Thirty-eight recipients of ICDs underwent sleep studies over a period of three years. Results showed high levels in the number of ventricular arrhythmias occurring simultaneous to disordered breathing, and ventricular arrhythmias occurring during the time of normal breathing in the sixteen patients (42%) with sleep-related breathing disorder. This result was unexpectedly high and further studies were
indicated. The effect of sleep disturbance on patients susceptible to VT may account for the peak of SCD episodes occurring during daytime hours when patients are undertaking daily life-function (Peters, McQuillan & Gold, 1999). The most recent findings located for this review, identified sleep disturbances as the greatest problem for ICD recipients and the medicated group. Sleep disturbances interfered with energy levels and emotional reactions (Carlsson, Olsson & Hertervig, 2002). An interpretive study of the experience of ICD recipients’ disturbed sleep and the effects on QOL would provide more information on the personal impact of sleep disorders on the sufferer.

Longitudinal studies have monitored ICD recipients’ QOL and well-being following SCD (Irvine et al., 2002; Kamphuis et al., 2002; Schron et al, 2002). The first aim of Irvine et al., (2002) was to compare QOL outcome between ICD recipients and medicated patients in the Canadian Implantable Defibrillator Study (CIDS), and second, to evaluate the effect of ICD shocks on QOL. The Irvine study used questionnaires to 317 participants over a twelve-month follow-up period and found an improved QOL in the ICD group in the areas: energy, physical mobility, emotional reactions, sleep disturbance, and lifestyle impairment, while shocks from the ICD interfered with overall QOL. Although questionnaires gather valuable insight into QOL, a more insightful study could be obtained by utilising follow-up personal interviews. Conversely, Hsu et al., (2002) found no significant change in QOL in a similar study of 264 participants. Hence, this would indicate the need for personal experience interviews.

Schron et al., (2002) conducted a similar study to Irvine et al., (2002) with 800 participants from the AVID Trial over twelve-months. The Schron study results contrasted with the Irvine study results in that there was decreased self-perceived QOL in each group as a result of adverse symptoms from medication and ICD shocks, decreased physical function, and decreased psychosocial well-being. In studies where ICD recipients perceive decreased QOL, these perceptions need to be explored for similarities and differences if a holistic picture of QOL is to be available for purposes of providing support by health professionals. The results from the Kamphuis et al., (2002) study, were more specific due to participants completing four questionnaires rather than two questionnaires. A similar study to Irvine and Schron, but with a smaller group of SCD survivors (n=168), Kamphuis claimed no difference in QOL between the two
groups. However, more specific results showed that older patients and women reported decreased QOL. Furthermore, anxiety and depression remained high regardless of treatment (Kamphuis et al., 2002). It is noteworthy that differences in questionnaires can influence statistical results. If health professionals are to be fully informed as to the depth of QOL-hazards, such as anxiety and depression, a study approach that includes a person’s unique expression of how implantation with an ICD effects QOL is vital. Phenomenological studies achieve experiential expression from participants that would assist health professionals to engage in support programs for recipients and significant others.

Questionnaire studies continue to be used to evaluate potential QOL-hazard using similar quantitative tools, similar participant age range (60 years), and similar male to female gender difference (2:1) in participants (Carroll, Hamilton & Kenney 2002). Carroll’s study findings showed no significant changes in QOL over one-year with seventy ICD recipients and concluded that the effects of living with an ICD are not well understood. Understanding a complex concept, such as QOL, is a philosophical underpinning of phenomenology. Thus, phenomenology may have revealed significant QOL issues that add to health professionals’ understanding of the phenomenon of implantation.

A different questionnaire instrument was used in the Australian context; 74 ICD recipient’s QOL-hazard was evaluated by using the well-validated Medical Outcome Study Short Form 36 (SF36) questionnaire (Pelletier et al., 2002). The authors concluded from the results that the negative impact of heart implantation with an ICD on QOL remains over time and impairs general health and social function. Furthermore, the overall impact of ICD shock on recipients and families has not been adequately addressed. In order to adequately address the overall impact of ICD shock therapy on QOL, an approach that asks recipients and family members to tell their individual story is imperative for evidence based practice by health professionals. One multinational study including 267 ICD recipients with the advanced DDD device, which is capable of pacing, sensing, and defibrillating atrial and ventricular arrhythmias, completed self-reported QOL assessments; a different type of instrument from the Pelletier study (Newman et al., 2003). There was no evidence that receiving shocks decreased QOL over a six-month period. Nonetheless, the authors were not prepared to
generalize their results beyond the study group and proposed that statistical results can be unreliable. Thus, there is an argument for interpretive studies that deal directly with a person’s experience in order to increase the knowledge base of health professionals.

Attempts to extend the lives of patients with congestive cardiac failure, has resulted in the MIRACLE ICD Trial (Multicenter InSync ICD Randomised Clinical Evaluation) completed in 2001 (Young et al., 2003). Cardiac resynchronisation therapy (CRT) through biventricular pacing has been combined with ICD therapy, the outcome of which is still unknown. The Miracle ICD Trial randomised 369 patients whose hearts were implanted with combination devices; 187 had the ICD and CRT activated. At six months, patients assigned to CRT had improved QOL. However, both groups managed only a six-minute walk. As an experimental study with experimental therapy there remains much work to be done before safety and efficacy in treating heart failure can be claimed.

The studies discussed under the heading QOL-hazard have, for the greater part, defined QOL within the parameters of a large number of QOL instruments. This has confined QOL perceptions and definitions within the researcher’s presumptions of what QOL can be for a generalised population rather than specifically for ICD recipients. For example, it is presumed that there is a QOL after SCD. The complexities of the human Being and the perceived meaning of QOL by an individual is a within-subjectivity that defies classification and measurement. This within-subjectivity is a phenomenon that only the unique Being can express from his/her frame of reference.

GAPS IN HEART IMPLANTATION KNOWLEDGE

Bioelectronic and clinical cardiology research have established the positive, life-extending capability of ICD therapy for people with life-threatening cardiac arrhythmias and SCD. Even though ICD therapy is costly, it is less economical to have patients frequently hospitalized and treated for these arrhythmias. There is a wealth of research that substantiates the benefits of heart implantation with an ICD for these purposes. There is also a vast array of empirical research that categorises, measures, and scales the physiological, psychological, social, and family dynamics consequences, associated with heart implantation with an ICD.
Every study in this area includes the word ‘implantation,’ or a derivative of implantation, many times. But the impact of this phenomenon of implantation remains a dynamic challenge. There is a substantial lack of personal perspective research on the impact that implantation for life-threatening arrhythmias has on patients, family members, and health professionals. Significant areas include, the impact of sudden cardiac death, the impact of life-threatening cardiac diagnosis, and the impact of heart implantation with a permanent ICD. Other important areas related to implantation include, the physical effects, the psychological effect, the social effects, and quality-of-life effects of ICD implantation on patients, family members, and health professionals. Moreover, research on the personal and professional attributes of health-care providers to benefit ICD patients and family members in the long-term, would be invaluable. These gaps in research, in relation to heart implantation with an ICD, need more focus on personal perspective in study approaches to cross the barriers between patients, family members, and health professionals.

If the real concern in this cardiac area were the recipient, the family members, and the health professionals, rather than the innovation and promotion of a multi-billion dollar industry, the research focus would turn to the human perspective. In this study I aim to fill a gap in knowledge in two ways. First, I will explore the meaning of implantation as presented in the personal perspectives of persons whose heart has been implanted with a bioelectronic ICD; in the personal perspectives of the person’s family members; in the personal perspectives of cardiac nurses and paramedical personnel; and in the personal perspectives of cardiologists. Second, this study will explore these perspectives on implantation through the philosophical approach of a hermeneutical phenomenology of implantation. The purpose of this approach is to promote a deeper understanding of heart implantation with an ICD by giving a voice to the key players in the phenomenon.

Chapter Three will outline in detail the methodology of this study, the methods I employed, why I chose the methods, how I applied the methods, and the outcomes of the research process as I progressed with the study.
CHAPTER THREE

THEORETICAL FOUNDATIONS:
RE-AWAKENING THE PHENOMENON

INTRODUCTION

Much time, consideration and discussion brings this study of implantation of a person’s heart with a permanent bioelectronic device to the starting point of ontology. Re-awakening a phenomenon is to bring the phenomenon to conscious exploration (van Manen, 1990). In this study, re-awakening the phenomenon of an electronically implanted heart means to explore the nature of the phenomenon. In other words, it means searching for the essence of the phenomenon that can reveal what it is. Re-awakening the phenomenon requires an exploration of and an interaction with a philosophical basis, an appropriate research methodology and philosophically grounded procedures of inquiry.

Philosophers such as Jaspers, Heidegger and Merleau-Ponty express concern for the advancement of technology and the absence of regard for how technological advancements hold meaning from a human experience perspective. Karl Jaspers (1961, p. 330) urges recognition “that technology, know-how, achievements, are not enough.” Heidegger (1966, p. 54) questions the human interaction with advanced technology in that “we can say ‘yes’ to the unavoidable use of technological objects, and we can at the same time say ‘no’ insofar as we do not permit them to claim us exclusively and thus to warp, confuse, and finally lay waste to our essence.” Merleau-Ponty (1964, p. 160) criticizes science’s lack of thought for the meaning of altering human existence through technology, described by him as “thinking operationally…a sort of absolute artificialism, such as we see in the ideology of cybernetics.” In addition, Merleau-Ponty advocates a return “to the site, the soil of the sensible and opened world such as it is in our life and for our body (…) that actual body I call mine. Further, associated bodies must be brought forward along with my body.”
The phenomenon of a person’s heart implanted with an ICD needs meaningful interpretation through “a truly embodied approach to the world” (Berman, 1986, p. 24). An embodied approach can offer insight into the humanness of the body experience and biotechnology. By focusing on the lived body to formulate Phenomenology of Perception (1962) Merleau-Ponty offers a phenomenology of the body and his existentialist thinking is relevant to a study of merging the person’s body with biotechnology. Thus, hermeneutical phenomenology is the approach of choice to facilitate a degree of understanding of the embodied experience as lived by the human beings involved in this study of heart implantation. The researcher is an integral part of phenomenology, therefore first person expression is used where most appropriate.

**Philosophical ontology and epistemology**

Questions about existence and the world are philosophical issues and clearly include both ontology and epistemology (Hughes, 1990). The question of what is in the world is a question of ontology. Related to the ontological question is the equally important question of what constitutes knowledge of the world, an epistemological question. Clearly then, issues of ontology and epistemology are interconnected. Inquiry into what exists in the world invariably leads to the question of how to go about making known what exists in the world.

Merleau-Ponty (1962) disputes the epistemology of science and argues for an epistemology of knowing phenomena in the world through the body. Science has been sustained by preconceived ideas about knowledge of the world and its phenomena (Merleau-Ponty, 1962). Interpretation of phenomena has been classified in rational, intellectual terms. Science interprets events in the world according to causal properties. Within classical science, what exists in the world is reduced to the status of an object (Merleau-Ponty, 1962). Consequently, the living body is equally reducible to an object like all other objects. This being the case, the body loses subjectivity and becomes a disembodied consciousness. However, Merleau-Ponty (1962) argues that scientific epistemology which goes unchallenged, equally, becomes uncertain of its absolute nature. This has occurred because technological advancement and the chaos of world wars pushed the boundaries of philosophical epistemology to a place where human
context, culture and history could no longer be ignored. Thus, phenomena that exist in
the world are open to rediscovery.

Merleau-Ponty’s (1962, p. 57) epistemology is a dialectical process that allows
phenomena in the world to be lived and interpreted through our embodied experiences.
The “first philosophical act” is re-awakening and rediscovering phenomena, as
individuals, other people and things come into being. Ontological questions and
epistemological questions are “the core of philosophy - the perpetual beginning of
reflection. Reflection is truly reflection only if it knows itself as reflection-on-an-
unreflective-experience, and consequently as a change in structure of our existence” in
the world (Merleau-Ponty, 1962, p. 62). Changes in existential structure can be found
by examining Merleau-Ponty’s philosophy. This study of the body and bioelectronics
explores changes in existential structure for the people involved in heart implantation.

Existential underpinnings drawn from Merleau-Ponty

The following anecdote makes clear the notion of the everyday, ordinary,
taken-for-granted, and pre-reflective experience. An ancient anecdote told by Aristotle
(in Heidegger, 1971) places Heraclitus (500 BC), a Greek philosopher, warming himself
at a fireplace. People waiting to hear words of wisdom are disappointed at this
mundane scene but Heraclitus urges them to ponder the everyday concrete situation they
so quickly dismiss. Heraclitus points out that the genesis of any genuine reflection must
be actual human situations, those situations in which human beings come to know their
own unique existence (Heidegger, 1971). One such human situation is the heartbeat
habitually beating until a life-threatening change of heart rhythm draws embodied
attention to the person’s continued existence or being-in-the-world.

Central to existential philosophy is the significance of considering the meaning of our
being-in-the-world and the importance of awakening awareness of our intrinsic
connection in a cultural, social, historical milieu (Merleau-Ponty, 1962). As researcher
I need to ask participants what implanting the heart means in terms of his/her milieu.
Each person’s perspective is influenced by individual milieux. Existential philosophy
contends that it is impossible to be non-situated and that knowing comes into being in a
co-existence with others as situated players in an open-ended lived relationship.
For this reason the present study includes the key people involved in implanting the person’s heart with an ICD; recipients, family members, cardiac nurses and paramedical personnel, and cardiologists. Furthermore, existential philosophy encourages human beings to live thoughtfully and to maintain participation in the shaping of situations in which they are fundamentally involved through existence (Merleau-Ponty, 1962). Hence, in this study participants are not neutral observers, but rather express through language the embodied phenomenon of heart implantation. While not claiming to access absolute knowledge, existential philosophy agrees that “philosophising starts with our situation” and seeks to illuminate the phenomena in our existence (Jaspers, 1971, p.158). Through the context of the body in the lived world, Merleau-Ponty’s phenomenology is an existential philosophy that can illuminate the phenomena in human existence, such as heart implantation.

THE PERSON AND EMBODIMENT IN MERLEAU-PONTY’S PHENOMENOLOGY

In opening Phenomenology of Perception (1962, p. vii) with, “What is phenomenology?” Merleau-Ponty leaves no doubt as to the path his work takes and the answer almost immediately follows by drawing on Husserl (1962). Phenomenology deals with essences and is a philosophy that returns essences to our lived experience or ‘facticity’ as it is before we try to make sense of it (Merleau-Ponty, 1962).

I am the absolute source…for I alone bring into being for myself … [the] point of view, namely that of consciousness, through which from the outset a world forms itself round me and begins to exist for me. To return to things themselves is to return to that world which precedes knowledge, of which knowledge always speaks, as is geography in relation to the countryside in which we have learnt beforehand what a forest, a prairie or a river is. (Merleau-Ponty, 1962, p. ix)

Returning to the things themselves as the absolute source of Being and existence is to return to the site of phenomena within our lived world. Because the source of knowing our existence is our body, all phenomena are experienced through our body. Thus, Merleau-Ponty’s (1962) phenomenology upholds the primordial bond between human beings and the phenomena in the world. Furthermore, his phenomenology seeks to draw our attention to this bond and to make it embodied. Merleau-Ponty (1962) continues to develop a phenomenology of perception and of the body with each
becoming inextricably the same in the notion of embodiment. Perception of the world and embodiment are intertwined because “inside and outside are inseparable. The world is wholly inside and I am wholly outside myself” (Merleau-Ponty, 1962, p. 407). In this way all phenomena in the world become part of the embodied person, as does the embodied person become part of phenomena in the world. This being so, the point at which the discussion has arrived is the concept of the intentional arc.

As part of the world a person’s Being is enmeshed with the intentional arc. Facets of the intentional arc include the existential tenets discussed by Merleau-Ponty (1962) such as temporality/time, spatiality/movement, emotionality, sexuality/gender, relationality, and corporeality.

The intentional arc

The intentional arc is the core of Merleau-Ponty’s philosophy of embodiment. It is the fundamental level at which the lived body and the lived world come together in the past, present and future. This study of the implanted heart epitomises how embodiment in illness is constantly in the present. The person’s past and future can be a mere heartbeat either side of the present. Merleau-Ponty (1962, p. 136) expresses the concept in illness:

The life of consciousness - cognitive life, the life of desire or perceptual life - is subtended by an ‘intentional arc’ which projects round to our past, our future, our human setting, our physical, ideological and moral situation, or rather which results in our being situated in all these respects. It is this intentional arc which brings about the unity of the senses, of intelligence, of sensibility, and motility. And it is this which ‘goes limp’ in illness.

There are many facets to the intentional arc. It ‘subtends’ the possibilities and the meanings within existence and situations. The intentional arc is like a continuum that presents many different possibilities within phenomena. This continuum also holds many different meanings of being-in-the-world. The intentional arc is the life of embodied consciousness; the life of time and space; it is the embodied unity of emotionality and sexuality; the intentional arc enables the person to have an embodied perspective on heart implantation. When intentionality breaks down in illness, the person’s world is fragmented. As Merleau-Ponty states above, the intentional arc combines our humanity, embodiment, values and beliefs, in the context of our present
situation. In addition, the intentional arc influences our body, perspective, emotionality and action. However, in illness the intentional arc ‘goes limp’ (Merleau-Ponty, 1962) and cannot sustain the person. Thus, in this study of heart implantation there is the possibility of embodiment, disembodiment and altered embodiment. Because intentionality is central to phenomenology, the phenomenological approach is relevant to wanting to know and understand the phenomenon that is heart implantation.

The existential modes of spatiality/movement and temporality/time

Merleau-Ponty (1962, p. 139) suggests, “our body inhabits space and time.” In other words our existence or being-in-the-world is embodied spatiality, embodied motility and embodied temporality. Spatiality through motility is “the way in which the body comes into being as a body” and is related to the project of “I can” and not “I think” (Merleau-Ponty, 1962, p. 137). Embodied movement always relates to the phenomenal body that moves within a context, against a background (Merleau-Ponty, 1962). This kind of movement can inform the present study of meaningful embodied phenomena in the world: “I am not in space and time, nor do I conceive space and time; I belong to them, my body combines with them and includes them. The scope of this inclusion is the measure of that of my existence” (Merleau-Ponty, 1962, p. 140). Implantation of the person’s heart means that the person lives with occupied body space and a heartbeat permanently timed to move as a measure of his/her existence. Merleau-Ponty’s (1962, p. 143) phenomenology discusses the habitual body and whether the person successfully adapts to technologies:

To get used to instruments [bioelectronic devices] is to be transplanted into them, or conversely, to incorporate them into the bulk of our own body. Habit expresses our power of dilating our being-in-the-world, or changing our existence by appropriating fresh instruments.

Here, Merleau-Ponty is discussing a person’s perspective, which encapsulates lived-space and lived-time. The person can be ‘transplanted’ or engulfed by bioelectronics or conversely, allow bioelectronics to become part of embodiment or disembodiment. Either perspective means that embodiment alters and our existence or being-in-the-world changes because of our perspective in relation to implanting the heart with an ICD. Similarly, as Heidegger (1966) argued, the person can say ‘yes’ to lifesaving bioelectronics or the person can say ‘no’ in a way that protects his/her
embodiment from being exclusively claimed by bioelectronics. In relation to space and time, both Merleau-Ponty and Heidegger caution that the person may become the lived-space and the lived-time that he/she allows to be occupied within the body. What will ‘dilating’ our being-in-the-world with ‘instruments’ of lived-space and lived-time mean to the person? Hence, Merleau-Ponty (1962) affirms how a phenomenology of the body can be appropriate in locating meaning that relates to implanting the heart with a bioelectronic ICD.

The existential mode of relationality

Relationality or lived other has been described as the communal, the social and the cultural (Merleau-Ponty, 1962; van Manen, 1990). This is because relationality is the lived connection between people in a shared lived world. Merleau-Ponty (1962, p. 353) explains lived other:

We have learned in individual perception not to conceive our perspective views as independent of each other; we know that they slip into each other and are brought together finally in the thing [phenomenon]. In the same way we must learn to find the communication between one consciousness and another in one and the same world. In reality, the other is not shut up inside my perspective of the world, because this perspective itself has no definite limits, because it slips spontaneously into the others’s, and because both are brought together in the one single world in which we all participate.

Once again Merleau-Ponty speaks about individual consciousness and perspective. Individuals co-exist in the same world and clearly are open subjects to each other. As such, there cannot be only one perspective, because individuals are connected in the same phenomenon, such as heart implantation. Merleau-Ponty (1962, p. 354) stresses that individuals are bonded in particular cultural phenomena that are our bodies and our dialogue. Individuals are connected to the extent they are as “two sides of one and the same phenomenon.” In relation to the body, consciousness and dialogue, “there is constituted between the other person and myself a common ground; my thought and his [hers] are interwoven into a single fabric.” Thus, I argue that an exploration of this study phenomenon needs the interwoven perspectives of those participating in heart implantation.
The existential mode of corporeality or embodiment

Embodiment cannot be separated from other existential concepts, such as lived space. Embodiment is defined by Merleau-Ponty (1962, p. 150), “I am not in front of my body, I am in it, or rather I am it. The body is the ‘effective law’ of its changes.” Living through our body informs us that we are embodied space in existence. Our body is connected to a certain world and is not in space, but rather the body is of space. Embodiment is the way in which we come into being as a unified body moving through the world. Regardless of visual and tactile evidence, we embody space, even through those invisible parts of the body. The arrhythmic heartbeat in this study is as embodied by the person as is the phantom limb, although neither is visible (Merleau-Ponty, 1962). Speaking of embodiment Merleau-Ponty (1962, p. 150) elaborates:

If we can still speak of interpretation in relation to the perception of one’s own body, we shall have to say that it interprets itself. Here the ‘visual data’ make their appearance only through the sense of touch, ‘tactile data’ through sight, each localised movement against a background of some inclusive position, each bodily event, whatever the ‘analyser’ which reveals it, against a background of significance.

So in this study of heart implantation the person feels, sees, perceives and senses the embodied data of each bodily event and interprets this data according to the significance and meaning these embodied events hold for the person.

Merleau-Ponty (1962, p. 150) also compares the body, “not to a physical object, but rather to a work of art” such as a picture, a piece of music, a poem or a novel. These modes of embodiment create an extended existence that makes them what they are. They convey expressions of words, accent, intonation, gesture and facial expression, which portray embodiment and essentially the fundamentals of existence. In these ways of embodiment, the body “is a nexus of living meanings.” Sexuality/gender and emotionality/language assist with knowing ways of embodiment.

The existential mode of sexuality/gender

Sexuality and gender are included in Merleau-Ponty’s account of existential significance and with specific expression of embodiment. They are important in understanding what it is to be human. Sexuality and gender impact upon the whole
person and influence our experience of the body as both a subject for us and as an object for someone else (Merleau-Ponty, 1962). Sexuality and gender are not restricted to relationships, but are more to do with those lived desires that spring from choice and intentionality. Being male or female is not about biological differences alone. Sexuality and gender, “without being the object of any intended act of consciousness, underlie and guide specified forms of my experience” (Merleau-Ponty, 1962, p. 169).

As a phenomenological study, this project is concerned with unique perspectives. Some perspectives of experience may be similar and others dissimilar. The phenomenon of heart implantation includes both male and female, with sexuality, gender and emotion, as key elements of being-in-the-world. Hence, describing “my whole body for me is not an assemblage of organs juxtaposed in space. I am in undivided possession of it (...) through a body image” (Merleau-Ponty, 1962, p. 98).

Hence, in this study of the implanted heart and body it will be seen through the grasp of meanings that sexuality, gender and emotionality are forms of original intentionality. While these modes of embodiment within the healthy subject endow vitality, when based on the intentional arc that breaks down in illness it is discovered there are internal links with the person’s being-in-the-world (Merleau-Ponty, 1962).

The existential modes of emotionality and language

Emotions are structures of intentionality expressed through language. The person’s past and future lived world is experienced in the present and his/her emotion can be expressed as fear of something (future) or angry with something (past) (van Manen, 1995a). Nonetheless the emotion is in the present and “the phantoms of internal experience are possible only as things borrowed from external experience” (Merleau-Ponty, 1962, p. 27). Expression of emotion through language can bring about deeper emotionality because of the inadequacy of conventional words to convey the complexity of a phenomenon. Conventional language lacks the scope to embrace the embodied experience of an electric current delivered to a person’s heart: “there are feelings in me which I do not name” (Merleau-Ponty, 1962, p. 296). Merleau-Ponty (1962, p. 379) speaks of people:

Being under the sway of situational values which conceal from them their actual feelings; they are pleased because they have been given a present, sad because they are at a funeral, gay or sad according to the countryside around them, and on the hither side of any such emotions, indifferent and neutral.
Merleau-Ponty’s comprehensive explanation of emotion is relevant to this study of heart implantation, because the situational values of people in relation to this phenomenon may vary dramatically.

In this section I have sought to show how Merleau-Ponty’s concept of the intentional arc interconnects with the four existential tenets of spatiality/lived space, temporality/lived time, relationality/lived other and corporeality/embodiment. Because this is a study of the body it was essential to include appropriate modes of embodiment such as sexuality/gender, emotionality and language. Such interconnections are imperative because it is the undertaking of interpretive phenomenology to uncover the structures of intentionality in relation to the embodied or disembodied person in this study.

**INTERPRETIVISM: A HERMENEUTICAL DIALECTIC**

Hermeneutics means to understand a text in such a way that allows for uncovering hidden or veiled meaning (van Manen, 1990). In this way hermeneutics is about language and expressed meaning, both known and unknown. It is “a method for deciphering indirect meaning, a reflective practice of unmasking hidden meanings beneath apparent ones” (Kearney, 1991, p. 277). Hermeneutics assumes a bond between a text and reader, a connection whereby meaningful interpretation becomes a possibility. Phenomena in a person’s lived experience lie beneath his/her words because meaning can only be implied in spontaneous language. It is the task of hermeneutics to discover explicit meanings, beliefs and assumptions that the person may find difficult to describe (Crotty, 1998).

In formulating this study as an interpretive phenomenology, I have had the benefit of looking to past projects that have used phenomenology. North American nursing projects have tended to favour the more descriptive approaches developed by phenomenologists such as Colaizzi (1978) and Giorgi (1970). However, the interpretive texts of philosophers such as Dilthey (1985) and Heidegger (1962) led to an informed choice. I decided that this study of body implantation needed to move beyond a descriptive project if the research question was to be explored to its full potential. I saw
this potential as reaching for the unknown meanings behind the description of the phenomenal body. In order to begin these research activities van Manen (1990) suggests turning our attention to the phenomenon to be investigated. Interpretive phenomenology offers this project the potential for an interpretation that embodies original possibilities for a deeper understanding of heart implantation and new knowledge for cardiac nursing.

**TURNING TO THE PHENOMENON**

Phenomenology always turns to the ontology of something. It asks what is the nature or meaning of the phenomenon of concern to the researcher. The topic for research relating to ICDs was not in doubt at any time. Phrasing the research question did create a time of searching before I was fully aware that the phenomenon of concern was implantation of a person’s heart with an ICD. The ICD, of itself, can have no meaning until it is given meaning by the people involved in heart implantation. It was enlightening to realize that I had travelled a circular mode of thinking where I had thought of embodiment as a phenomenon, only to realise that embodiment needs to be embodiment of something. Phenomenology requires “the same demand for awareness and the same will to seize the meaning of the world as that meaning comes into being” (Merleau-Ponty, 1962, p. xxi). The demand for awareness in phenomenology includes the phenomenological reduction (Merleau-Ponty, 1962).

**Phenomenological reduction**

Knowing the object of investigation from both a personal perspective and a professional perspective (See chapter one), I needed to unknow or engage in a reduction of previous knowledge to be true to the phenomenological perspective (Crotty, 1998). Reduction is necessary because my experiential knowledge of the cardiac life-world is unique to me as an embodied person. My experience is not transferable to any other person nor is his/her experience transferable to me. Any interpretation arising from this study will be one interpretation amongst many possibilities (Munhall, 1994).

The phenomenological device of reduction allows us to discover a spontaneous world even though a complete reduction is not possible. Merleau-Ponty (1962, p. xiv) assures
us “that in order to see the world and grasp it as paradoxical, we must break with our familiar acceptance of it and, also, from the fact that from this break we can learn nothing but the unmotivated upsurge of the world.”

van Manen (1990) identified four levels of reduction from Merleau-Ponty (1962). First, reduction stirs a deep sense of wonderment at the fundamental dialogue between body-subject and the world. This “wonder” is profoundly dynamic and “reveals that world as strange and paradoxical” (Merleau-Ponty, 1962, p. xiii). Second, in the reduction it is necessary to reflect on previous experiences and suspend our preconceptions of the lived world. Not that we reject the validity of our experiences “but because, being the presupposed basis of any thought, they are taken for granted, and go unnoticed, and because in order to arouse them and bring them to view, we have to suspend for a moment our recognition of them” (Merleau-Ponty, 1962, p. xiii). Third, the reduction requires exposing scientific theories and abstractions that would prevent the phenomenon of concern being viewed with meaningful insight. In this way we are adhering to Merleau-Ponty’s (1962, p. xv) directive: “Looking for the world’s essence is not looking for what it is as an idea once it has been reduced to a theme of discourse: it is looking for what it is as a fact for us, before any thematisation.” Fourth, in the eidetic reduction we need to reconcile the particular and the universal in the study phenomenon to enable seeing the essence that will answer the research question. The world is full of ambiguity and “the eidetic reduction is the determination to bring the world to light as it is before any falling back on ourselves has occurred, it is the ambition to make reflection emulate the unreflective life of consciousness” (Merleau-Ponty, 1962, p. xvi).

Having grappled with the research question and reflected on my own understanding and preconceptions of the research phenomenon (chapter one), I felt free to turn my attention to the world of heart implantation.

TURNING TO LIVED-WORLD EXPERIENCE

While the philosophy of Merleau-Ponty (1962) underpins this study because of the emphasis on understanding the person as an embodied being, I have drawn on van
Manen (1990) to guide a creative research project. Although other phenomenologists such as Heidegger and Sartre, are cited by van Manen (1990), it is clear that Merleau-Ponty significantly influenced his methodology. Critics of interpretive phenomenology, such as Gadamer (1989), who point out the absence of method were answered by van Manen (1990, p. 30) in the following way:

> While it is true that the method of phenomenology is that there is no method, yet there is a tradition, a body of knowledge and insights, a history of lives of thinkers and authors, which, taken as example, constitutes both a source and a methodological ground for present human science research practices. Thus the broad field of phenomenological scholarship can be considered a set of guides and recommendations for a principled form of inquiry that neither simply rejects or ignores tradition, nor slavishly follows or kneels in front of it.

There are many paths to knowing in phenomenology (Munhall, 1994). In this study I have chosen to refer to the notion of data as dialogue. Whereas data implies a quantitative notion, dialogue implies reciprocity wherein giving and receiving takes place (van Manen, 1990). In a phenomenological study I agree with van Manen (1990) that I need to look, listen and read whatever material in the life-world will engage me in a dialogue of reflection on the phenomenon that is heart implantation.

To achieve a body of knowledge and insight in this study, I chose to draw on personal experiences from recipients of ICDs and their family members, cardiac nurses and paramedical personnel, and cardiologists. I sought to engage these groups of people in face-to-face dialogue where possible, because they are the people who possess the experiential knowledge of heart implantation. In circumstances where face-to-face dialogue was not possible I chose to utilise alternative modes of dialogue, such as telephone dialogue and email dialogue. Experiential description in the dialogue of literature, film and art can also yield something valuable as to the nature of heart implantation. These phenomenological sources bring the research question to life and “the narrative of being here, being there, and being-in-the-world” is enriched (Munhall, 1994, p. 58).

**OBTAINING EXPERIENTIAL DESCRIPTIONS**

The quality of experiential descriptions depends on the ability of participants to express specific events that relate to the phenomenon being studied (Sandelowski, 1999). The
articulation of expressive language often means that potential study participants may most appropriately be of adult age. Retrospective and on-going events are a source of quality experience because participants have the benefit of time in which to view events as lived. Recruitment of participants while still in the throes of an event, such as heart implantation, contravenes the study ethic to minimise harm. Such participants may not be suited to the study purpose for epistemological reasons. Epistemologically suitable participants are obtained through the process of selection criteria. The criteria for selection as a participant who was a recipient of an ICD included the following, which are similar to criteria suggested by Morse (1991):

- Participants had experienced living with their heart implanted with an ICD for three months or longer.
- Participants were living within the community.
- Participants were able and receptive to articulating their lived experience of the phenomenon.
- Participants were eighteen years of age or older.

I chose to engage in dialogue with participants from four groups. Implantation of a person’s heart with a permanent ICD is a human experience involving four interconnected groups of people: the recipient, his/her family members, cardiac nurses and paramedical personnel, and cardiologists. Each group experiences the implantation of a person’s heart from a different perspective. I chose these four groups of people (recruitment is discussed later in this chapter) because they embody the phenomenon that is implantation of the person’s heart and body with a permanent ICD. Their experiential embodiment of the phenomenon emanates from different perspectives, which pull together in developing a deeper understanding of the phenomenon of heart implantation.

The selection criteria for family members of recipients who live the phenomenon from a different frame of reference, was derived from criteria listed for recipients.

- Participants lived with or near to their family member who is a recipient of an ICD.
- Participants were living within the community.
- Participants were able and receptive to articulating their lived experience of the phenomenon.
- Participants were eighteen years of age or older.

Selection criteria for cardiac nurses and paramedical personnel, and cardiologists were based on experience with ICD recipients.
- Cardiac nurses were required to be registered nurses.
- Cardiac nurses and cardiologists had cardiac care experience with recipients of ICDs for a period of at least one year.
- Cardiologists needed knowledge and/or experience in cardiac care with recipients of ICDs.

Having made decisions about potential participant selection to ensure the ultimate quality of this study would be contingent with the appropriateness of participants’ involvement in the research phenomenon, I chose to go public with the area of study. I chose a community based, participant recruitment strategy because I believed potential study volunteers who made contact would have experiential narratives to tell in relation to their heart, body implantation and the ICD. In addition, with regard to ethical issues, discussed later in this chapter, I believed ‘going public’ with the study was appropriate because participation would stem from each person’s own volition.

**Going public to recruit all participants**

Quantitative researchers have been utilising multiple techniques for recruiting participants and collecting data for many years (Roberts & Woods, 2000). In relation to facilitating dialogue within a qualitative study, the use of modern communication technology such as, broadcast media, newspaper and journal print, telephone, electronic email and the Internet, is now acceptable and successful as a research activity (Cooper, 2000; Gaiser, 1997; Rezabek, 2000; Roberts & Woods, 2000; Whyte & Watson, 1998).

Following ethical approval from Griffith University, Brisbane, Australia, I approached the University Media Unit, briefly outlining the need for a more in-depth understanding of the lived-world of people involved in the phenomenon of heart implantation with a permanent ICD. I collaborated with the media unit journalist who organised to release the study outline on the University Media Release Website. Journalists with access to the website took an interest in this study. Subsequently, three radio stations included a discussion on this study in separate human-interest programs. Likewise, several local newspapers printed articles.

An 1800 free-call telephone number had been arranged and the resulting contacts from within the community were encouraging. Where community-based participant
recruitment is utilised, major challenges, such as using planned multiple sources and engaging the professional communities, along with the media, are encountered (Schoenfeld et al., 2000).

The result of going public, via the mediums of speaking on live radio and newsprint articles by journalists, was disconcerting. While the response from the public was encouraging, I found that people who made contact were unsure as to whether they were recipients of cardiac pacemakers or ICDs. Even though I had explained the difference between pacemakers and ICDs, both on the radio and in the study outline in the media release, knowledge about the devices in the general public appeared to be lacking. Although unexpected, this outcome served to strengthen my conviction that there was a substantial need for this project. Conversations I had with callers on the free-call number provided, dealt with recipients of pacemakers who wondered whether their device was a pacemaker or an ICD. Other callers stated that their general practitioner knew very little about implantable cardiac devices, such as ICDs. At this point I did not have any contact from health professionals.

With this study ‘out there,’ I contacted a struggling support group for ICD recipients and explained the project to the person acting as gatekeeper. The possibility of this study was welcomed. Most of the study participants who were recipients of ICDs (group one) learned about this study through networking within the group. The existence of this study was included in the group’s mailed newsletter and featured on their website. The group’s feeling toward this research was one of validation of the need for the study. The chairperson verbalised the feeling in this way: “We have been waiting for someone like you to come along.”

All efforts up to the point of selecting participants had been directed towards securing a purposeful sample for “phenomenal variation” (Sandelowski, 1995, p. 181). I was searching for experience-rich individuals in the target phenomenon. People are the sources of lived-through phenomenon and I engaged in a snowball technique that would add more potential participants to this study. The snowball technique involved participants in all groups passing on my 1800 free-call number and my email address.
Recruiting recipients of ICD as participant: (Group One)

Networking with the self-help support group over a period of six months, resulted in eight study participants within group one. Thereafter, Griffith University published a follow up article, in The Griffith Gazette. This article resulted in accessing a further recipient who was included in the study, bringing the total number of recipient participants to nine. There were two recipients who did not have a receptive family member willing to participate in this study (Dialogue Table One).

Recruiting family members as participants: (Group Two)

Family members were the easiest participants to recruit for this study. When a participant from group one was receptive to this study, in most cases there was a family member who was also receptive. In one instance, three members of the same family became participants. Family members also enabled access to a further two recipients of ICDs who became participants. Group two consisted of eleven family members. Two family members were also recipients of heart implantation (Dialogue Table Two).

Recruiting cardiac nurses and paramedical personnel as participants: (Group Three)

Strategies employed to recruit cardiac nurses included submitting an article to Critical Times, a publication of the Australian College of Critical Care Nursing and writing a letter to the editor of Queensland Nurse. These endeavours included an invitation for cardiac nurses to participate in this study. Networking with the nurses who responded resulted in a successful snowball technique and further recruitment. Registered nurses included in this study numbered fourteen.

I was surprised that recruitment of cardiac nurses was more time consuming than I had expected. Leighton-Beck (2000) cautions that the rewards of networking can take time. Instilling interest and raising research awareness in busy clinicians (Hundley et al., 2000), through writing and verbal communication, was a challenge that eventually proved worthwhile. I believe one of the contributing factors to success in recruiting cardiac nurses for this research was the assurance that I was interested in their personal
perspective rather than an organisational perspective. Thus, cardiac nurses felt reassured of privacy and confidentiality. Group three consisted of Registered Nurses and all had extensive cardiac care experience of more than five years.

Through networking, two paramedical personnel involved with recipients of ICDs, a Clinical Psychologist and a Exercise Physiologist, were included in group three as participants because of their close professional relationship with cardiac nurses (Dialogue Table Three).

**Recruiting cardiologists as participants: (Group Four)**

Passive recruitment (Holloway & Wheeler, 1996) was utilised for potential cardiologist participants. Study Information Sheets and a Consent Form (Appendix G & D) together with a cover letter were mailed to cardiologists (n=27) listed in the telephone directory of an Australian city. Two weeks later this initial contact was actively followed up with a telephone call. Where an email address was available electronic communication was also utilised. My efforts to include this group were met with significant silence, some humour and a little success. Medical silence tends to disembodied the person who is titled cardiologist in this study. The absence of voice speaks of disembodiment as discussed in an article entitled, Dr. No-body (Gothill & Armstrong, 1999). Networking resulted in interest from several overseas cardiologists through the medium of electronic email. Three Australian cardiologists and three overseas cardiologists became participants in this study (Dialogue Table Four).

Networking took the form of one or more participants from each group recommending the study to insiders (Morse, 1991). Insiders are those who have experiential involvement and knowledge of the phenomenon being researched. Thus, as already outlined, all participants for this study resulted from both a volunteer and snowball technique (Morse, 1991; 1994). Networking meant that I was already engaged in phenomenological dialogue with potential participants.
On-going communication with all participants

All potential participants were provided with the relevant Study Information Sheets and Consent Form (Appendix D, E, F, G). Consent Forms were identical for each group, while Study Information Sheets were similar and headed Recipient, Family Member, and Health Professional. Except in the case of overseas cardiologists in this study, all participants were personally contacted by telephone to establish a degree of rapport, answer any questions and to elicit a place and time most suitable for dialogue. The same courtesy was extended to those participants who required telephone dialogue. During this courtesy communication I was able to assess whether potential participants were within the parameters of predetermined selection criteria. After going public with this study it was my intention to utilise, where possible, an unstructured, face-to-face, phenomenological dialogue style of communication (van Manen, 1990).

Phenomenological dialogue

In phenomenological research the focus on the phenomenon of concern requires collaborating with study participants to ‘borrow’ their lived experiences (van Manen, 1990). In this study of heart implantation with an ICD, I believe the depth of personal perspective, required to deepen understanding from an embodied view, calls for the person’s own expression of language. While I sought to be informed of the participant’s experience, the purpose of dialogue in phenomenology is to remain in touch with the question of the nature of the phenomenon as the core of an essentially human experience (van Manen, 1990). Other sources of insight such as The Liminal Body, literature, poetry, and film, speak their own phenomenological dialogue. Thus, I feel it is appropriate in this study to describe data collection activities as phenomenological dialogue. To enhance the understanding of any phenomenon Sandelowski (2002, p. 104) advocates the embodiment of other dialogues and cautions against relying on the “precariousness of a one-legged stool” (Hall & Rist, 1999) over the sturdiness of the four-legged chair. Merleau-Ponty (1962, p. 178) describes a phenomenological dialogue in this way:
People can speak to us only a language, which we already understand, each word of a difficult text awakens in us thoughts which were ours beforehand, but these meanings sometimes combine to form new thought which recasts them all, and we are transported to the heart of the matter, we find the source.

**Phenomenological dialogue with recipients of ICDs (Group One)**

The first phenomenological dialogue was with the acting gatekeeper of the support group I contacted. In essence, this description is basically identical to all other dialogue with people in this group.

Dialogue began with a telephone call to the participant to engage in a general conversation in relation to introduction, to get a feel for the participant’s readiness to discuss the proposed research, to establish initial rapport and to request a meeting. The details of comfort and convenience, such as time and place were left open for the participant to choose according to informed consent. The familiar context of home was chosen. It was agreed that study information sheets and consent forms could be forwarded by email attachment. Prior to travelling to the participant’s home I made a courtesy telephone call to confirm the convenience of the meeting and the wellbeing of the participant.

In this first encounter, the participant, family member and I began our dialogue by watching a patient education video owned by the participant. Study questions were dealt with and consent forms signed. Permission to audiotape the dialogue was confirmed and the family member went out for the afternoon.

The phenomenological dialogue followed three phases. First, I asked the participant to “tell me what events led up to you being told you needed an ICD.” This statement solicited a self-story from the participant. During this story I was appropriately silent except for murmurings of acknowledgement and encouragement. I made brief notes that required exploration. Second, at the end of the self-story, I explored experiential areas by asking, “What was it like…?” Third, I asked phenomenological questions such as, “What did that mean to you?” “How did you feel about that?” and “Can you give me an example of…?”
Participants preferred extensive first dialogues, ranging from one hour to two and a half hours, with shorter follow up dialogues (Dialogue Table One). Siedman (1998) reassures that there are no absolutes in a dialogue procedure and that little research has been carried out in this area. I believed my responsibility was to respect the wishes of participants. Participants in this group lived in both metropolitan and regional Australia, and had cardiac implantation procedures in both public and private hospitals.

**Dialogue Table One: Recipients of ICDs**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age Range</th>
<th>Dialogue 1</th>
<th>Dialogue 2</th>
<th>Dialogue 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jay</td>
<td>50-60</td>
<td>19/12/00</td>
<td>Email</td>
<td>Email</td>
</tr>
<tr>
<td>Jock</td>
<td>50-60</td>
<td>05/01/01</td>
<td>Email</td>
<td>None</td>
</tr>
<tr>
<td>Hugh</td>
<td>50-60</td>
<td>27/06/01</td>
<td>Email</td>
<td>None</td>
</tr>
<tr>
<td>Stan</td>
<td>40-50</td>
<td>10/01/01</td>
<td>Email</td>
<td>Email</td>
</tr>
<tr>
<td>Jade</td>
<td>30-40</td>
<td>01/04/01</td>
<td>Journal</td>
<td>Email</td>
</tr>
<tr>
<td>Simon</td>
<td>20-30</td>
<td>16/01/01</td>
<td>Email</td>
<td>Phone</td>
</tr>
<tr>
<td>May</td>
<td>20-30</td>
<td>28/02/01</td>
<td>Telephone</td>
<td>Email</td>
</tr>
<tr>
<td>Noel</td>
<td>20-30</td>
<td>10/04/01</td>
<td>Email</td>
<td>None</td>
</tr>
<tr>
<td>Dell</td>
<td>20-30</td>
<td>24/01/01</td>
<td>Telephone</td>
<td>Email</td>
</tr>
</tbody>
</table>

**Phenomenological dialogue with family members (Group Two)**

The recipients of ICDs who were receptive to being participants approached their family members in this study. Recipients then notified me of their family decision. Family members who agreed to contribute to this study were spouses, mothers, fathers, and one sister (Dialogue Table Two). All initial dialogue with family members was located according to the preference of the participant. Elements of the dialogue process such as contact, rapport, informed consent and dialogue duration applied to family members as explained for recipients of ICDs. Family members were asked to give their rendition of events leading up to their loved one being told that heart implantation with an ICD was considered necessary. Five family members had been witnesses to loved-ones’ sudden cardiac death experience. Similar phenomenological questions to those asked of group
one, were asked of family members. One family member/recipient gave permission for me to read her journal in place of a second dialogue.

**Dialogue Table Two: Family Members**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Relationship</th>
<th>Dialogue 1</th>
<th>Dialogue 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pam</td>
<td>Spouse</td>
<td>28/12/00</td>
<td>Phone</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Home</td>
<td></td>
</tr>
<tr>
<td>Bev</td>
<td>Spouse</td>
<td>05/01/01</td>
<td>None</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Home</td>
<td></td>
</tr>
<tr>
<td>Kara</td>
<td>Spouse</td>
<td>22/01/01</td>
<td>Telephone</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Home</td>
<td></td>
</tr>
<tr>
<td>Deb</td>
<td>Spouse</td>
<td>16/01/01</td>
<td>None</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Home</td>
<td></td>
</tr>
<tr>
<td>Beth</td>
<td>Sister</td>
<td>14/02/01</td>
<td>Telephone</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Coffee Shop</td>
<td></td>
</tr>
<tr>
<td>Scott</td>
<td>Father</td>
<td>21/02/01</td>
<td>Email</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Home</td>
<td></td>
</tr>
<tr>
<td>June</td>
<td>Mother</td>
<td>21/02/01</td>
<td>Email</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Home</td>
<td></td>
</tr>
<tr>
<td>Bill</td>
<td>Father</td>
<td>20/03/01</td>
<td>None</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Office</td>
<td></td>
</tr>
<tr>
<td>Jill</td>
<td>Mother</td>
<td>15/03/01</td>
<td>Email</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Telephone</td>
<td></td>
</tr>
<tr>
<td>Zoe</td>
<td>Spouse</td>
<td>16/07/01</td>
<td>None</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Telephone</td>
<td></td>
</tr>
<tr>
<td>Jade</td>
<td>Mother</td>
<td>01/04/01</td>
<td>Journal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Home</td>
<td></td>
</tr>
</tbody>
</table>

**Phenomenological dialogue with cardiac nurses and paramedical personnel (Group Three)**

The fourteen cardiac nurses who became participants in this study had extensive experience and knowledge about heart implantation with an ICD. These participants worked as cardiac nurses in three states of Australia, in a total of eight separate hospitals, both public and private (Dialogue Table Three). Included in this group of health professionals were a clinical psychologist and an exercise physiologist, both of whom worked with patients who experienced heart implantation with an ICD. While most of these participants were familiar with research activities such as surveys, they needed time to consider phenomenological style dialogue. The phenomenological question, “Can you give me an everyday example of that?” often prompted the
response, “Umm, I don’t know.” I found that patience and rephrasing was the key to eliciting a response that was phenomenological in essence. I asked these cardiac nurses, “Would you have your heart implanted with an ICD?” It was a question that required considerable reflection. For most of this group, one dialogue spanning one to two hours was all the time they could spare. The location of preference for engaging in dialogue for this group was a combination of their own home, their office, telephone, and email.

**Dialogue Table Three: Cardiac Nurses and Paramedical Personnel**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Profession</th>
<th>Dialogue 1</th>
<th>Dialogue 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jody</td>
<td>Registered Nurse</td>
<td>29/01/01 Telephone</td>
<td>Home</td>
</tr>
<tr>
<td>Rick</td>
<td>Clinical Psychologist</td>
<td>30/01/01 Office</td>
<td>None</td>
</tr>
<tr>
<td>Lea</td>
<td>Cardiac Nurse</td>
<td>06/02/01 Dialogue Room</td>
<td>None</td>
</tr>
<tr>
<td>Roy</td>
<td>Exercise Physiologist</td>
<td>06/02/01 Dialogue Room</td>
<td>Telephone</td>
</tr>
<tr>
<td>Rolf</td>
<td>Cardiac Unit Manager</td>
<td>06/03/01 Telephone</td>
<td>Telephone</td>
</tr>
<tr>
<td>Sue</td>
<td>Cardiac Nurse</td>
<td>13/03/01 Dialogue Room</td>
<td>None</td>
</tr>
<tr>
<td>Adel</td>
<td>Cardiac Nurse</td>
<td>14/03/01 Home</td>
<td>Telephone</td>
</tr>
<tr>
<td>Jill</td>
<td>Cardiac Nurse</td>
<td>15/03/01 Telephone</td>
<td>Email</td>
</tr>
<tr>
<td>Laura</td>
<td>Cardiac Support Nurse</td>
<td>15/03/01 Telephone</td>
<td>Email</td>
</tr>
<tr>
<td>Rae</td>
<td>Cardiac Nurse</td>
<td>28/03/01 Office</td>
<td>Telephone</td>
</tr>
<tr>
<td>Clare</td>
<td>Cardiac Nurse</td>
<td>29/03/01 Home</td>
<td>None</td>
</tr>
<tr>
<td>Amy</td>
<td>Cardiac Nurse</td>
<td>21/03/01 Telephone</td>
<td>Telephone</td>
</tr>
<tr>
<td>Gay</td>
<td>Cardiac Nurse</td>
<td>06/04/01 Telephone</td>
<td>None</td>
</tr>
<tr>
<td>Guy</td>
<td>Cardiac Nurse</td>
<td>03/04/01 Telephone</td>
<td>Telephone</td>
</tr>
<tr>
<td>Kay</td>
<td>Cardiac Nurse</td>
<td>03/04/01 Telephone</td>
<td>None</td>
</tr>
<tr>
<td>Fay</td>
<td>Cardiac Nurse</td>
<td>05/04/01 Telephone</td>
<td>Telephone</td>
</tr>
</tbody>
</table>
Phenomenological dialogue with cardiologists (Group Four)

It took time and persistence on my part to be successful in a small way in carrying out a phenomenological dialogue with cardiologists (Dialogue Table 4). I asked phenomenological questions, such as “What does the heart mean to you?” and “What do you think of the concept of dying naturally?” The imbalance of power when posing a personal or evocative question to a participant, who is often viewed as a member of an elite group, is a tangible thing (Odendahl & Shaw, 2002). While remaining respectful of participants’ rights, I found that a calm voice and direct eye contact assisted with negotiation of what was sometimes a power-laden situation. Situations encountered included “the experience of being rebuffed, turned down, ignored, and dismissed” (Price, 1999). As with all participants from each group, I adopted a naïve stance and approached phenomenological dialogue with “curiosity, openness without preconceived assumptions seeing the participant as the expert in meaning making” (Kvale, 1996, p. 31).

Overseas cardiologists (Dialogue Table Four) who indicated by email their interest in this study, were sent phenomenological questions such as, “What is it about the human heart that influenced you to choose the heart as your field of specialty?” and “What is your personal opinion about implanting the human heart with a bioelectronic device such as the ICD?”

**Dialogue Table Four: Cardiologists**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Specialty in Australia</th>
<th>Specialty Overseas</th>
<th>Dialogue 1</th>
<th>Dialogue 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bob</td>
<td>Cardiac Surgeon</td>
<td></td>
<td>18/12/00 Telephone</td>
<td>None</td>
</tr>
<tr>
<td>Gary</td>
<td>Interventionist Cardiologist</td>
<td></td>
<td>24/04/01 Office</td>
<td>None</td>
</tr>
<tr>
<td>Sean</td>
<td>Interventionist Cardiologist</td>
<td></td>
<td>16/05/01 Office</td>
<td>None</td>
</tr>
<tr>
<td>Neil</td>
<td>Cardiologist Ethicist</td>
<td></td>
<td>14/05/01 Email</td>
<td>None</td>
</tr>
<tr>
<td>Zane</td>
<td>Cardiologist</td>
<td></td>
<td>22/05/01 Email</td>
<td>None</td>
</tr>
<tr>
<td>Rhys</td>
<td>Cardiologist Ethicist</td>
<td></td>
<td>23/09/01 Email</td>
<td>Email</td>
</tr>
</tbody>
</table>
Ethical considerations

In this study, which deals directly with a person’s heart, my principal aim when seeking to dialogue with potential participants was to do no harm. During my first contact dialogue with the gatekeeper of the support group, my approach portrayed sensitivity and humility. Indeed throughout the research activities I felt privileged to be trusted with the embodied experiences of human beings. I believe I established a quality relationship with all participants based on sensitivity to the ebb and flow of their emotions. This emotional component was brought to the attention of all participants in study information sheets and prior to arranging dialogues. My priorities have been respect for all participants’ right to autonomy and confidentiality, a comfortable rapport, open-ended communication and consideration for their time and convenience. During times of emotion I allowed all participants space, silence, and patience. The name and contact number of a clinical psychologist for referral was available in the event of any participant experiencing emotional distress. The occasion did not arise where referral was needed.

All participants’ autonomy in this study was protected through the snowball and volunteer techniques. In this way participants gave permission to a third party to pass on their contact details. For example, one Nurse Unit Manager made contact with the name, appointment time and work phone number for several cardiac nurses who had volunteered to be participants. Thus, these participants expected and welcomed my follow-up. However, most volunteers made contact with me on their own account. In addition, all participants were in possession of consent forms until convenient dialogue times were arranged. Selection criteria, especially for non-professional participants, took into account the language expression of the person and served a dual purpose. First, it assured the ability of the person to enter into sensitive dialogue. Second, it assured a level of individual comprehension and subsequent protection in relation to study information sheets and the signing of a consent form (Fischman, 2000). One potential participant was not followed up because of a communication problem with conceptual understanding, which may have compromised informed consent.

All participants were reminded that central to protecting privacy was the right to refuse to participate, continue with the study, withdraw completely from the study, and to
refuse to answer a specific question (Folkman, 2000). For example, all participants were assured that if a question caused them discomfort they were not obliged to respond. Confidentiality is best described as the deletion of identifying names and places from dialogue transcripts, and any published material. This was discussed with all participants prior to dialogue and included in the study information sheets. Confidentiality was discussed in relation to how personal information solicited from all participants during the study would be protected (Sieber, 2000). Pseudonyms were used for all participants and I chose to use Christian names, because this was the way we communicated. Verbatim excerpts from all participants will be accompanied by a pseudonym.

In this study I chose not to profile any participants, because others knew some participants within each group and a profile may have breached confidentiality. Confidentiality was maintained in that I personally conducted each audio taped dialogue, typed my own transcriptions and kept all disks and hard copies of study dialogue locked in my home office. This commitment will be kept for five years. While all attempts are made to safeguard confidentiality, it was explained to all participants that verbatim excerpts are utilised in phenomenological studies.

An area of threat to confidentiality is the use of email (Sales & Folkman, 2000). In instances when I needed to utilise email communication I checked security efficacy with the other party. However, most of the primary data for this study came from face to face, phenomenological dialogue. In all phenomenological dialogue with participants from each group, the general principles of ethics were adhered to.

Adhering to ethical principles

Humanistic research such as phenomenology is an ethical goal in itself (Sieber, 2000). This section discusses the five general principles of ethical conduct in the process of research with human participants (APA, 2001). The aim of the principles is to guide researchers to aspire to the highest ethical ideals and conduct. These principles include:

- Beneficence and non-maleficence
- Fidelity and responsibility
- Integrity
- Justice
- Respect for peoples’ rights and dignity

Beneficence means taking care to do no harm. I achieved beneficence by safeguarding the welfare of research participants, such as their physical, psychological and social wellbeing in such a way as to minimise or avoid harm (Sales & Folkman, 2000). I took due care to be sensitive to any potentially negative consequences for the research participant, which constitutes non-maleficence.

Fidelity and responsibility are encapsulated in the Study Information Sheets and the Consent Form. There was an explicit and implicit agreement of trust, between myself, and participant, which was morally binding. Researchers accept the responsibility to individuals, groups and society, to fulfil their commitment to the agreed project as fully as possible. Fidelity was achieved by trust in the way I recognised the autonomy of participants (Husted & Husted, 1995).

Integrity entails veracity and veracity was fundamental to the way I protected participants’ privacy and rights. My truthfulness and accuracy in research reporting promoted trust in communication and interaction throughout the research process (Folkman, 2000).

Justice ensures that research participants and their families continue to receive the highest possible quality of care and standard of health services in accordance with their right to participate as much, as little or not at all, throughout the research process. I ensured that participants exercised autonomy through informed consent. I followed the highest quality of care as described by Smith and Veatch (1987, p. 7), “autonomy is the moral basis for the legal doctrine of informed consent, which includes the right of informed refusal.”

I demonstrated respect for participant’s rights and dignity, which included the worth of all participants regardless of differences, such as culture, age, gender, religion and socio-economic status. All participants had the right to privacy, confidentiality, self-determination and autonomy throughout the research process (Fischman, 2000).
Tracing etymological sources

Etymological origins of words reverberate with the lived meaning that keeps words alive across time (van Manen, 1990). Searching for etymological sources of words central to this study meant that vocabulary texts, such as The New Oxford Dictionary of English (Pearsall & Hanks, 2001) and the website, http://www.dictionary.com/ were examined. Unlocking the origins and meanings in words, such as implantation, heart, embodiment and electricity, directed attention to the underlying values and distortions in language. Merleau-Ponty (1962, p. 178) describes the nature of language as “the word, far from being the mere sign of objects and meanings, inhabits things and is the vehicle of meanings.”

Incorporating literature, poetry, film, art, and idiomatic phrases as dialogue

Our language expression reveals rich insights for phenomenological reflection. Merleau-Ponty (1962, p. 179) concludes that “there is thus, either in the man who listens or reads, or in the one who speaks or writes, a thought in speech the existence of which is unsuspected by intellectualism.” In this study I was interested in what the heart meant to people in relation to the phenomenon of implanting the heart with an ICD. I explored many literary sources in the modern Western World for material that related to the existentials being explored in this study and for idiomatic phrases that included the word heart in order to gain a deeper understanding of how the heart is embodied by human beings. I was constantly aware of any reference to the heart or any heart-related illness in film, poetry, art and literature. This engagement with meaning to be found about the phenomenon of interest has been referred to as “the eternal dialogue” (Munhall, 1994, p. 39). Other dialogues discussed by Munhall (1994) are the external dialogue with participants, explained above, and the internal dialogue with the textual data that other paradigms refer to as data analysis.

HERMENEUTIC PHENOMENOLOGICAL REFLECTION

The importance of phenomenological reflection is described by Merleau-Ponty (1962, p. 177) as: “A thought limited to existing for itself, independently of the constraints of speech and communication, would no sooner appear than it would sink into the
unconscious, which means that it would not exist even for itself.” Having dealt with the epistemological source of the phenomenon through dialogue with participants, I turned to the ontological task of phenomenological reflection. The ontological task in phenomenology is to uncover the structures of meaning that the dialogue with participants contains. Continued reflection on the dialogue meant many readings of transcriptions, beginning with the very first through to some fifty separate dialogues. The purpose of this activity was to gain “insight into the essence of a phenomenon involv[ing] a process of reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience” (van Manen, 1990, p. 77). In order to bring this study of heart and body implantation to an understandable and meaningful writing of prose, I began to write and rewrite each piece of phenomenological reflection that was meaningful. In this way I was able to see multiple meanings that were approached as themes.

Identifying themes

The notion of theme offers some direction to phenomenological writing about the phenomenon of study while allowing the creativity of “insightful invention,” “discovery” and grasping what it is like to be human (van Manen, 1990, p. 79). Themes are embodied in the data text, in the imagery and in the metaphors (Sandelowski, 1998a). Merleau-Ponty (1962, p. 179) speaks of themes as bringing “the data retrospectively to light as convergent.” Moreover, “the fact is that we have the power to understand over and above what we may have spontaneously thought…where we discover an unknown quantity through its relationship with known ones” (p. 178). Thus, being immersed in participants’ dialogue became part of my lived-world for many months.

In the process of engaging in dialogue with participants and typing my own transcriptions of participants’ dialogue, I found immersion in the dialogue text was not a concern. I found myself agreeing that, “knowledge in qualitative inquiry often is said to come from deep immersion with data, profound commitment to purpose, and prolonged engagement with research participants” (Sandelowski, 1998b, p. 467).
The auditory stimulation of listening to audio taped dialogue gave me a sense of the whole experience for each participant, while making notes provoked my thoughts on specific experience. I was assisted by the three activities of thematic analysis suggested by van Manen (1990, p. 93; 1995b). First, when I began working with hard copies of the data text, I engaged in holistic reading and made several attempts to write a “sententious phrase” as to what the text epitomised on a fundamental level. Second, in a highlighting approach, I read the texts several times and marked those statements that spoke directly about the phenomenon of heart and body implantation with an ICD. Third, I examined each sentence in relation to experiential description of the study phenomenon. In this way I sought to identify possible themes of lived experience. The phenomenological task was then to extract verbatim excerpts that gave phenomenological substance to selected themes.

While excerpts from transcriptions confer validation on themes, the phenomenological writing is enriched by original language expression (van Manen, 1990; Sandelowski, 1986). The point of following these activities was not to claim a phenomenological process, but rather to approach the text in a way that may “hold promise in rendering human experience interpretable and understandable in our present time and place” (van Manen, 1997, p. 345).

After the first few dialogues with participants, I realised this study was taking an existential direction towards lived-body. The existential direction was not surprising given the phenomenon of concern. Hence I was led by the text to write notes and transformational dialogue that was “existential, emotive, enactive, embodied, situational, and non-theoretic” (van Manen, 1997, p. 345). While focusing on the thematic aspect of the text, I searched for meaning that held “tension between what is unique and what is shared, between particular and transcendent meaning, and between the reflective and the pre-reflective spheres of the life-world” (van Manen, 1997, p. 345). This tension brings power to hermeneutic phenomenological writing through five textual features van Manen (1997) refers to as lived-throughness, evocativeness, intensity, tone and epiphany.
HERMENEUTIC PHENOMENOLOGICAL WRITING

The meaning in phenomenological writing is in the reading (Richardson, 1994) and the capturing of the “surprise of a recognisable person” (Miller, 1994, p. 503). If the language used in phenomenological writing lacks evocativeness then the writing of interpretation may read more like traditional science. Insightful writers such as Morse (1997), Sandelowski (1994a), and van Manen (1990; 1995a; 1997) agree on a more artful, creative and evocative form of writing about what it means to be human:

It is as if, in our quasi-militaristic zeal to neutralise bias and to defend our projects against threats to validity, we were more preoccupied with building fortifications against attack than with creating the evocative, true-to-life, and meaningful portraits, stories, and landscapes of human experience that constitute the best test of rigour in qualitative work (Sandelowski, 1993, p. 1).

The five textual features discussed by van Manen (1997) do not organise the writing of text but rather encourage moving beyond the everydayness of language. I was inspired to examine how the dialogue text spoke to me in conjunction with what it said.

First, lived throughness is the concrete experience of the world that the reader of phenomenological writing can recognise as part of everyday living. Merleau-Ponty (1962, p. xvii) clarifies that “the world is not what I think, but what I live through. I can never completely account for the facticity of what assures me of my existence.”

Second, evocation serves to bring lived experience vividly to view for phenomenological reflection. Vividness in phenomenological writing aims for intuitive interpretation of text. In working with themes, I attempted not only to describe a concrete experience but also to evoke vivid images of the study phenomenon.

Third, intensification in phenomenological writing gives full meaning to significant words in relation to the topic, such as heart and implantation. I attempted to achieve intensification through the photograph of a chest x-ray (front page) and by exploring participants’ use of poetic devices such as word repetition and metaphors. Merleau-Ponty (1962, p. 178) encourages intensification, stating: “The fact is that we have the power to understand over and above what we may have spontaneously thought.” For example, during dialogue with participants I felt silence as a stillness...
with the room wrapped in the sounds of silence. During transcriptions of taped dialogue the stillness and silence could be heard.

Fourth, tone is when the phenomenological text speaks to the reader in a way-of-knowing deeper meaning on a non-cognitive level. I welcomed the opportunity to include in this study a poetic dialogue with a nurse (Appendix H). The lines of the poem spoke a dialogue that was filled with an inner level of meaning. While remaining true to the essence of heart and body implantation I aimed to write a phenomenological text with a captivating and compelling tone.

Fifth, epiphany needs to be the special effect of tone in phenomenological writing. Epiphany brings about a transformative experience of understanding. The phenomenological language of epiphany evokes images that reach the core of the reader. I experienced many epiphanic moments when dialoguing with the data text of participants. These moments of epiphany I attempted to write in a way that will be “understood a study of the phenomenon of the poetic image when it emerges into the consciousness as a direct product of the heart, soul and being of [readers], apprehended in [their] actuality” (Bachelard, 1994, p. xviii). I believe it is by writing closely connected to ontological and epistemological concerns that this study can achieve rigour.

RIGOUR/TRUSTWORTHINESS IN A HERMENEUTIC PHENOMENOLOGICAL PROJECT

Rigour means the quality of being accurate and thorough (Pearsall & Hanks, 2001). Positivist paradigms can be accurate and thorough by adhering to issues of validity and reliability in the quest for objective truth. However, in a hermeneutic phenomenological project the quest is to gain moments of meaning in phenomenal experience. Hence, I provided meaningful reality from participants in this study that demonstrates trustworthiness in the findings. In this study I have utilised the philosophical phenomenology of Merleau-Ponty (1962) to underpin the research process and to produce a reflexive project. Merleau-Ponty states the philosophical stance on rigour in phenomenology:
I am not the outcome or the meeting point of numerous causal agencies, which determine by bodily or psychological make-up. … I cannot shut myself up in the realm of science. All my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view, or from some experience of the world without which the symbols of science would be meaningless. The whole universe of science is built upon the world as directly experienced, and if we want to subject science itself to rigorous scrutiny and arrive at a precise moment of its meaning and scope, we must begin by reawakening the basic experience of the world of which science is the second order expression (Merleau-Ponty, 1962, p. viii).

Questions of philosophical rigour can be answered by ensuring the method of inquiry is underpinned with the values and beliefs that will result in a phenomenological project (Koch & Harrington, 1998). This principle applies to all facets of the research process. The language used in this study is intrinsic to its success as a phenomenological activity, from the choice of research question throughout all the activities of method (Koch, 1999). To this end I ensured that the language employed throughout the study was congruent with the existential nature of the inquiry. In addition, I achieved a trustworthy audit trail through the imperative that the pathways of participant recruitment, dialogue engagement, reflection on dialogue text and interpretations formed, are congruent with the philosophy guiding the project (van Manen, 1990). Koch and Harrington (1998) instruct researchers to incorporate a reflexive style of writing that signposts for readers where the research is going. I formulated a creditible audit trail in this study through a well signposted project that leads the reader “through the worlds of the participants and makers of the text and [allow them to] decide for themselves whether the text is believable” (Koch & Harrington, 1998, p. 887).

I maintained rigour in the interpretive process by remaining part of the phenomenon being studied. In hermeneutic phenomenology the writer is located within the hermeneutic circle that is interpretation. I achieved trustworthiness by sharing with the reader of the research text how he/she and the participant move in the hermeneutic circle “between a background of shared meaning and a more finite, focused experience within it” (Thompson, 1990, p. 243). In this study I established trustworthiness through confirmability in identifying movement and dialectical interaction between the whole and the part, and subsequently offering interpretation (Denzin, 1989). By informing the reader about movement within and interaction with the text, I believe I produced a rigorous, ontological project. However, as Denzin (1996, p. 237) argues: “This
complex world, with its multiple perspectives, is then connected to a constantly changing external world, in which nothing is firm or certain. Consequently there can be no single truth.”

The constantly changing world of the recipient of heart implantation, the key player in this study, is thrown into focus in the following chapter.
CHAPTER FOUR

INTERPRETING THEMATIC PERSPECTIVES IN RECIPIENTS’ DIALOGUE

INTRODUCTION

After being in dialogue with recipients of implantable cardioverter defibrillators (ICD) for twelve months through reading and rereading their transcripts and writing numerous thoughts during times of reflection and spontaneity, I felt I had reached a point of understanding where thematic perspectives (van Manen, 1998) began recurring. As I engaged with recipients’ dialogue, all emerged as onerous. Thus I returned to verbatim transcripts and engaged in further reflection. I felt a similar connection with the dialogue from family members, cardiac nurses and cardiologists. I will engage with these thematic perspectives in chapters five, six, and seven.

While engaging in spoken and written dialogue with recipients, I also sought to embody other sources of dialogue-artefacts, such as film, literature, art and poetry, as mentioned in chapter three. Hence, during this engagement with recipients’ experiences with the phenomenon of implantation, the existential themes of, implantation as body-liminality, body-temporality/time, body-spatiality/movement, body-emotionality, body-sexuality/gender and body-relationality, will be supported and enriched with the sturdiness of in-the-world artefacts (Sandelowski, 2002). Table One outlines the existential perspectives, which became major themes, together with existential sub-themes or modalities. These concepts have been expressed as “modalities of body experience,” (van Manen, 1998, p. 7) and “modalities of existence” (Merleau-Ponty, 1962, p. 161). Because of the richness of expression in recipients’ dialogue, it was imperative to be both singularly and collectively selective in verbatim excerpts.
Thematic Concepts: Table One

<table>
<thead>
<tr>
<th>Existential Thematic Perspectives</th>
<th>Modalities of Existential Themes</th>
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<tbody>
<tr>
<td>Implantation as body-liminality</td>
<td>Hybrid persons</td>
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<td></td>
<td>Threshold people in ‘other’</td>
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<td></td>
<td>body-liminality</td>
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<td></td>
<td>Being betwixt and between life and death</td>
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<td></td>
<td>Being on the brink of life and death</td>
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<tr>
<td>Implantation as body-temporality/time</td>
<td>When time stood still</td>
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<td></td>
<td>When time went racing by</td>
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<tr>
<td>Implantation as body-spatiality/movement</td>
<td>Being disembodied within special spaces</td>
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<td>Being inside-in-the-world</td>
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<td>Being outside-in-the-world</td>
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<tr>
<td>Implantation as body-emotionality</td>
<td>Anxiety and fear: Like waking up into a nightmare</td>
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<tr>
<td>Implantation as body-sexuality/gender</td>
<td>Interfusion between sexuality/gender and existence</td>
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<td></td>
<td>Female sexuality/gender invaded and violated</td>
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<tr>
<td>Implantation as body-relationality</td>
<td>Body-Invalidation by health professionals</td>
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<td>Being validated by family members</td>
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<td>Validation of the ICD</td>
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Liminality

The concept of liminality originated in Arnold van Gennep’s (1960) formulation of rites of passage. Liminality marks a significant change of Being-in-the-world such as, being separate, being on the margin, or ‘limen:’ Latin for threshold. Turner (1986) developed the concept to include being betwixt and between, having left past embodiment of self yet not arriving at future embodiment of self. David Riesman (1954) had previously written of people who were unable to embody the identities expected of them in various cultures. Participants in this study who had experienced the phenomenon of heart implantation with an ICD wandered in a liminal search for self-definition and felt disembodied by who or what they had become. Thus, within a hermeneutic struggle I arrived at the thematic concept of ‘hybrid persons.’ This means that identity can never again be wholly organic or completely bioelectronic but a merging of the two. There may be occasions when hybrid and cyborg are used interchangeably in the following chapters.
“Wow! My God, is that real? I thought it was a trick! It is not the sort of thing you expect to see.” This was the response of a young female, university photographer, when viewing the chest x-ray of one of the recipients of an ICD in this study. Arrangements had been made to photograph the chest x-ray as a visual, tangible, hermeneutical representation of the phenomenon of implantation. If Dilthey (1976, p. 161) had seen The Liminal Body at the front of this thesis, he may have stated; “reality only exists for us in the facts of consciousness given by inner experience.” Bruner (1986) may have argued that words have outweighed the visual and language has become more valued than image. The image of the photograph is an expression of interpretation, engagement with body hybridisation and placement in liminality. It enters into a dialogue with the viewer that evokes a medley of responses including spontaneous shock and disbelief.

**Hybrid persons**

One of the participants in this study, May, portrayed hybridisation in a brief yet graphic, disembodied account of the organic and the inorganic. When entities recognised as belonging to different domains become fused in the body, then hybridisation occurs (Werbner & Modood, 1997).

> I had the surgery. They took the pacemaker out from the left hand side. The veins had closed around the wires. They had to put the ICD in the right hand side during the same surgery. They put two new wires in, so when I woke up I had two lots of surgery, each side. And I was sore. And I can still feel them. My x-ray would have to be bionic. I have four of the leads and wires. I still have all the tie wires around my breastplate.

This experience began with explantation of the inorganic object from May’s body, but complete separation from past hybridisation was not to be. A permanent fusion between body and object “wires” meant that the inorganic object maintained a presence within her body. This presence may be viewed not as a side effect of implantation; it is the very life of it. Implantation of May’s heart and body with the ICD further complicated body-liminality. Together with “tie wires” from past open heart surgery, May saw her body as “bionic” in the image of her chest x-ray. May’s confusion with what was real is evident in her naming her sternum as a “breastplate.” The sternum is
part of the organic body while a breastplate is a metal plate of armour (Pearsall & Hanks, 2001). As a hybrid person May was altogether lost in body-liminality.

When May first saw her own liminal body in its hybrid form she rushed about in disbelief showing the x-ray to everyone she knew. May needed to be convinced that her inner experience actually was her reality. Haraway (1990; 1993) argued that cyborgs are equally mythological and real. The mythological part of cyborg was unbelievable while the reality was “shocking.” By showing people her x-ray May hoped for validation of her disbelief. How could this shocking image actually be real or a true reproduction of what had been done to her body?

When I came out of hospital I made a point of showing everyone that x-ray. It was like I needed to show everyone you know, look at me! Look at what has happened to me … isn’t this shocking! It was like a ridiculous need. Yeah, I needed to show everyone I came across. Look at my x-ray. I guess it was like trying to help me get used to the idea of what was in there. It was whacky I know, but it went way beyond what was normal.

May’s photograph of her chest x-ray could have been an entry in a symposium of body photographs titled ‘The Liminal Body.’ This symposium of seven international photographic artists was held at the Australian Centre for Photography (ACP) in Sydney, Australia, and sponsored by the University of New South Wales. At this time the world celebrated the Olympian body striving for supremacy beyond the limitations of the every day body. In contrast, the photo-artists presented corporeal works “from medieval medical machinery to virtual ‘genital modification’; from the cadaver to the spiritual; from the catharsis of nightmare to the control of meaning; the body on the brink of life and death” (ACP, 2000, p. 1).

I said to people, “I apologise but I have to show you this x-ray.” But at the time I think it was so shocking for me that I just had to show other people to get their reaction and talk it through. [Reactions] … ranged from raucous laughter, you know, that someone could have so much wiring and still look normal, to absolute white-faced shock and feeling sick, and people would turn away.

While May reached out to people for catharsis from the nightmare image of her liminal body in its hybrid form, implantation meant neither life nor death, as mentioned in the ACP symposium, but something betwixt and between the two. People laughed in shocked embarrassment, people were white-faced with horror, people looked ill and people turned away. Liminality was not a place people wished to enter.
In contrast Dell was passionate in not wanting to see her liminal body at any time and would rather have destroyed it. During our dialogue I asked Dell to go back to the time of implantation. Her response was immediate.

Even just that word is horrible. That makes me think like, a little alien … implanted like the movie Alien. They implanted her with an alien. That is what it felt like. Yes. It was. It is. That is exactly what it was like. This little alien that I HATED and I would dream at night that I was putting my hand in my chest and ripping it out and throwing it off the side of a cliff. I absolutely HATED it with a passion. I begged them every time I went to see the [cardiologist] … please take it out, please take it out. I don’t want it. I just felt wrecked. I felt destroyed. I felt like I had been painting [her image on canvas] and someone had just drawn a knife down through it.

May and Dell were both able to enter into a hermeneutical dialogue of experiences they had lived through in relation to the phenomenon of implantation. Both spoke of disembodied image; an image in the form of an x-ray and a metaphorical image of a destroyed self-portrait. In both hermeneutical images there were similarities to Oscar Wilde’s portrait of Dorian Gray (Cornish, 1993) in which self and other co-existed but remained disembodied. Although May, Dell and Dorian Gray were endowed with extended life, they lived in horror of their own image.

May and Dell were also similar in portraying bioelectronic devices which were indeed the reality of implantation. The experience of heart implantation was “foreign,” “evil,” “alien.” How can the horror effect of implantation for people, such as May and Dell, be understood and interpreted? This can only be achieved by drawing on relevant elements within our culture. Margaret Lock (1995, p. 391) wrote about the paradox of mixing self and other and warned that the “Shiva like character of invasive biomedical technologies: potential creators of happiness but, at the same time, destroyers of society as we know it: for it is now possible to manipulate nature/culture and self/other dichotomies of long standing - projects confined thus far to the realm of fantasy.” Shiva is The Ultimate Reality in Hinduism, believed to possess the dichotomous powers of reproduction and dissolution (Pearsall & Hanks, 2001). May related her experience of implantation, much of which has remained unchanged.
Yeah, when I first got it, I hated it, loathed it, detested it. I wished I hadn’t bothered with it. It was difficult to get used to. The size of it…it felt like ten times the size. It was more the fact that it would move. It would move around when I went over a bump in the car. I would have to hang on to it. It made me hate it. I loathed it. It was definitely there … you could experience it. The foreign body inside me … it was more intrusive than I thought. It moved; it was unnatural. It is not supposed to be there. It was never intended to be there. Lying in bed at night and feeling and seeing it jutting out. UGH! I would give myself the creeps. I didn’t like being by myself at first because I was scared if it goes off, what will happen if I am by myself. Once I was over the pain and the skin or whatever, it [ICD] began to twitch, TWITCHING. It was scary, to stand in the shower and watch this machine jumping out.

May’s account is an example of culture and nature colliding in a person’s genuine irrationality. Yet May’s account reads similar to a classic horror novel by award winning author Ira Levin - Rosemary’s Baby (Levin, 1967). Lines from Levin’s novel on evil (I can no longer associate; It gives me the creeps; Its like a wire inside me getting tighter and tighter; Its moving, its alive) correspond so closely to May’s dialogue that it is possible to identify the cultural influence on her terror. To place the ICD within a rational context it is necessary to see the ICD for the object it is. The ICD is electronic with action potential, thus it is capable of moving and twitching. However, the reality of the ICD as an object cannot ever negate the reality of terror in May’s experience. While Dell likened her hybrid person to having the miniature alien implanted within the human body of Lieutenant Ripley in the science fiction phenomenon, Alien (Fincher, 1992), May’s description was more cybernetic in that she referred to “this machine.” Nonetheless, implantation of their hearts with the ‘other’ within their bodies brought horror, disgust, hate and terror into their lives.

May compared her scary experience to an experience of a different kind, convincing her that the implantation phenomenon was not natural.

A very good girlfriend had a baby. When she was extremely pregnant I could watch it [baby] moving in her tummy. That wasn’t disgusting because it was natural and normal and exciting and supposed to be happy. But this [ICD] was not. There was nothing natural and normal and happy about this. It was so foreign and weird and wrong and … yeah, you know.

May and Dell both compared and contrasted their experience of the implantation phenomenon with the evidence of a living entity within the body. However, Dell’s
contrast was of the science fiction kind where Lieutenant Ripley was to become the mother of the alien baby that Ripley destroyed in order to save the world from alien invasion. Dell’s affinity with Ripley was that she wanted to destroy herself and the alien within, by suicide. Dell also drew on the cyborg concept in the film The Terminator (Hurd, 1984) to give meaning to her body experience.

I felt like … have you ever seen Terminator? That steel object you know, the steel robot? It has that layer of skin over the top of it. When he cuts into himself, he is a metal object underneath. And that is how I felt. I don’t know if it was a fear of what would happen to me if I were by myself. I was scared of my ICD going off. If I had someone there to distract me, I could put aside my suicidal thoughts. As soon as that person went away, and the house was quiet, straight away I would just want to go and find a knife.

Simon spoke of science fiction when in dialogue about his experience of implantation by referring to Robocop (Schmidt, 1987).

I’m not really fussed with it. I’m cool. I guess you hear about it, you think of Robocop or whatever. I am waiting for them to grow me a heart. You ask someone who is healthy whether they think they should grow hearts and things like that, and then you ask someone who has some sort of problem and is on a waiting list for something … you get two very different opinions.

Unlike the Terminator who was incapable of feeling pain or emotion, Robocop was a reconstructed human being who experienced cybernetic hybridisation that saved his life, yet disallowed him to function as a cultural Being. Devices, such as the titanium suit, were used in the film to create the illusion of an alternative reality, however disembodied. Simon’s reality was that he would endure the implanted heart until medical science furthered the genetic code of human existence. The Human Genome Project has encouraged the belief that editing the molecular code can alter, erase, revise, and reproduce like a computer program or a printed text (Lee, 1991).

Noel was familiar with the cyborg concept. “I have a machine inside me that can do these terrible things to my body.” His subsequent laugh was sardonic. “Ah, science fiction! Star Trek sort of thing. I don’t have to like it. But I accept that it can save my life and has saved my life.” Implantation trapped liminal bodies in a bittersweet hybridised dichotomy where, to preserve life, terrible things needed to be endured. Whatever the outcome of future science, hybrid persons represented by May, Dell, Simon and Noel, would remain betwixt and between life and death, disembodied by implantation and subsequent body-liminality.
Threshold people in ‘other’ body-liminality

Implantation of the heart and body is a surgical procedure. As with all surgery there is the ever-present risk of infection. Hugh and Noel had not only the indeterminate hybrid-body disrupting their lives, they were to find themselves in another liminal existence that Victor Turner (1969) described as ‘threshold people.’ The liminality of these two men was to include a further level of threshold being-in-the-world when they experienced a “staph infection” post implantation.

They just take you in, put it [ICD] in and sew you up. But I did have a problem. After mine went in I got golden staph. I was in hospital for 3 months to get rid of the staph. Two of us got implanted the same day. (…) they had to take his [ICD] out again. They could not clear the infection up and leave it [ICD] in there. It certainly … it affects you psychologically. It has taken from 1999 till now and I am just coming down off anti-depressant tablets. Even now it affects me. (…) It was devastating (Hugh).

Acquiring nosocomial wound infection after the implantation of Hugh’s heart and body, as well as suffering memory loss after a sudden cardiac death episode, was powerful in its body-devastation. The post implantation infection complicated Hugh’s experience of liminal detachment from his known-body and the powerful feelings of devastation drained his resilience. In his distress Hugh was unable to reflect on devastation. Noel described his experience with nosocomial wound infection.

The scar tissue was all pus and stuff like that. The infection looked like open pus that didn’t look like it was going to heal. It was very liquid. My mother had Discord Lupus and I saw a lot of her body was very pusy where she was losing her skin and flesh. It kind of reminded me of those times when I used to change her bandages. It wasn’t a pleasant experience.

Nosocomial wound infection is not only a state where the body is dislocated in a wasteland of liminality; it is also a no-person’s-land where there is no illness classification and, therefore, no health system responsibility (Gardner, 1998). In the above excerpt this is demonstrated by Noel being the one who took responsibility for changing his mother’s bandages. Patients with “liquid,” discharging wounds are disembodied by an invasive entity that is foreign to the body-as-previously-known. Noel equated his disrupted, leaking, and socially unacceptable body to that of his mother’s. In losing skin and flesh the body is broken-down to reveal a persona as Victor Turner (1969, p. 95) observed, “it is as though they are being reduced or ground down.” It was as though the foreign organism coupled with implantation in an attempt
to separate the body from the integrity of skin and flesh. Conversely, the body “opened up” in response to invasive and foreign ‘other’ in an attempt to expel the unwanted entities that rendered the body as “not a pleasant experience.”

**Being betwixt and between life and death**

This section represents the deeper level at which heart implantation with an ICD became a presence of anguish to all recipients. This deeper level of other body-liminality drew all recipients in this study into the “black” of depression. Dell’s time of depression led her to the brink of suicide where she existed betwixt and between life and death.

I just climbed straight into the deepest depression. I was so depressed. I was suicidal. I wanted to be dead. The fact that I had always anticipated being dead at 22, and the fact that I wasn’t, was strange in the fact itself … apart from having a metal object in my chest that I absolutely hate.

Dell’s Ars Moriendo, ‘The Craft of Dying’ (Stark, 2001), had begun when she was a child. Medieval Christian tradition concentrated on becoming intimate with death as a way of understanding and preparing for the moment of leaving the body. “I discovered that I was going to die when I was twelve years of age. Quite a few people told me this. Several doctors.” After a near death experience, Dell had accepted and prepared for death as nothing to fear. Dying was part of Dell’s living and was represented by the peace and the “upward light” she had already experienced. “Reaching my 22nd birthday was quite an amazing event for me. Besides I knew I was pretty much down to a matter of days then, and I was just leading a very merry life style. Making the most of every single day, every second. I was having a wonderful time.” The double apprenticeship of living and the art of dying (Lamont, 1973) was Dell’s Ars Moriendo. The art of dying was “fact” in Dell’s belief system. However, the “fact” of heart implantation with an ICD became Dell’s reality. Consequently, she felt her body was “wrecked” and “destroyed.” The ICD was the symbol of her absolute “hate.” Dell had served her apprenticeship of living “every second,” only to be cheated of the art of dying. Thus, she considered her alternative dissolution.

I spent hours walking along the train line just wanting to jump. Hours and hours. (…) I would just be wanting to slice my wrists. (…) I thought I’d drive over the (…) bridge and maybe just turn my wheel and slip off the side and it would look like an accident. (…) Geez, I was tempted.
Dell wanted the ICD removed, “please take it out,” but family and the cardiologist refused her pleading, “you will die!” In a state of depression Dell, whose intention was to transform life into nothingness, turned to objects of everyday living, such as a train, a knife, a car. In the paradox of how objects are used “we go to the opposite extreme by distorting our own contribution in perception so as to make of it a power of creating ex nihilo [nothingness]” (Merleau-Ponty, 1962, p. 23).

In contrast, after facing mortality from numerous perspectives Dell arrived at a place where she thought of suicide as meaning “quitter.”

> While I don’t condemn people who suicide, I do understand, far too closely, how they do it. You have got to love someone other than yourself, more. I’d rather take whatever, and live with it [ICD], no matter how unhappy I am, than upset everybody else to that extent.

What was it about implantation of the heart with an ICD that compelled Dell to be aggressive in the pathology of suicidal intention? The biological and psychological discontent that has been socially constructed as suicide is very real (Hacking, 1999). While all recipients in this study were not as aggressive in their discontent as was Dell, all suffered deeply in their reality of implantation. For example, Jade “was a heavy smoker. I thought well, stuff it. I didn’t particularly care if I died, really.” Dell elaborated on what depression meant. “Black. Black. No one can help you. To see the world functioning around you, but you are not part of it. Depression is like hell. My own idea of hell … if I were to go to hell, it would be that black depression.” The nature of heart implantation replaced one life threatening illness with another, thereby sustaining liminality, betwixt and between life and death.

The sacrosanct privilege (Hacking, 1999) of a person’s body is part of life, and how life is lived is part of the determination of what kind of body a person identifies with.

> My vision of it [ICD] is a metal object just waiting in there. Waiting in my chest to get me when I was not expecting it … in ways to take me down, when I didn’t want it to. …My whole body. My heart being far more important than any other part of my body … and it is alien. You know when it actually did discharge I could taste metal in my mouth for days afterwards. It was really bizarre. That is it. For me it [ICD] is like that big [arms wide] and it took up that much space. The scar was a huge, big, red, ugly, horrible thing. It is not natural to have a metal object in your chest.
Dell was not able to accept the agonising responsibility for what had happened to her body, as she perceived, against her will. Dell envisioned the ICD as a threat to the sacrosanct privilege of what her body meant to her as a person. In this way Dell’s perception was correct. The ICD could and would “take me down” at any time. Dell’s sense of taste persisted in reminding her of the power that the ICD maintained over her body and her living. An alien object within the most treasured space of her body invaded her lived situation. Its bizarre presence could be tasted, felt exaggerated in size, and held a supernatural component in Dell’s perception. Dell reflected more on being “not natural.”

It is like evil. It is an unknown entity. It is sort of like a … it is not a natural object compared to a flower. I think that is very much how I felt. I felt like I was something natural but had been halved open and the inside of me was then replaced with something not natural, and evil in a sense. To have to recover yourself from that, when it takes up so much space.

Perceiving the body as the epitome of all things natural and good, such as a “flower,” lays the foundations for devastating dichotomies, such as “replaced with something not-natural” and likened to “evil.” Again, the body was located in a liminal place where body-identity and reality were blurred. Dell and other recipients perceived their bodies as blossoming in the beauty of youth, only to be “open” to a sense of malevolence.

All recipients in this study became depressed in their struggle to “recover” from a sense of malevolence. In her journal Jade wrote, “I feel I am on the road up the melancholy mountain again;” Hugh “was becoming hard to live with. I was up to 200mgs [antidepressant] a day;” Noel “could not get to sleep so I would get up and play [computer] games until it distracted me. I really needed distraction;” for Jock “it has been a total change of lifestyle;” Stan “was pretty screwed in the head. You go and approach somebody and they just tell you to piss off;” Simon felt “by the end of it I was all bitter and twisted;” May “went into a period of depression … Yeah, it was definitely a depression;” Jay’s cardiologist recommended “an anxiety disorder clinic. I don’t think the medical problems were as bad as the psychological … I have negative thoughts and feel depressed;” Dell added meaning to the effects of implantation.

Nothing is good, you hate yourself, you hate everything about yourself, you can’t bear to look at yourself, you don’t want to be near you, you don’t like yourself as a person. You can see everyone else, but you feel totally alienated, like you are in a glass jar. There is no laughing or smiling when you are depressed.
Being in a “glass jar” could be an analogy for Virginia Woolf’s (1948) metaphor of the body as a glass sheet through which the soul can only gaze at the body-situation. In illness melancholia we cannot know our own body or any other. “To look these things squarely in the face would need the courage of a lion tamer; a robust philosophy; a reason rooted in the bowels of the earth” (Woolf, 1948, p. 10). Hence, heart implantation alienates a person in body-liminality where boundaries between “depression,” “black,” “hell,” “nothing,” and “alienation,” are but a blur.

**Being on the brink of life and death**

Accounts of being in intensive care units (ICU) portray how impersonal, invasive, modern technology compels a person to grapple with the most intimate issues and questions regarding mortality (Frank, 1995). Being in a coma after a sudden cardiac death episode exerts tension on the bonds between bodies and persons and on the boundaries between the living and the dead. Hugh experienced three sudden cardiac death episodes and each time his heart was revived before nature separated his person from his body. Although Hugh could “remember nothing” of his ICU experience, he was aware that his failed heart had taken him to the brink of irreversible death.

> The heart is life isn’t it. Your heart is your life. I mean it is not like you can do without it. It is not like losing a kidney or something like that. It is the centre point of life.

Margaret Lock (2000, p. 234) wrote; “the altruistic act of organ donation permits meaning to be created out of sudden death.” This is where dispute involves nature and culture, the belief in the site of living or dying, or the believed ‘vegetable’ returning to functioning life. Such was the experience of Dell after a second episode of sudden cardiac death. Prior to implantation Dell was to make the transition across body-liminality; being between life and death.

> I was in a coma and on a life support machine. The doctors spoke to Mum and Dad about organ donation. They warned them that I might be a vegetable. Vegetable to me means being like a piece of this grass [plucked a piece of grass]. You are there, but you are not taking part in the conversation. … Just there, part of the scenery.
Futility is a term often used in ICU when a person is defined as qualitatively having a poor quality of life in the future (Goh & Mok, 2001). The predicted outcome for the psychological wellbeing of a person given the definition of ‘futile’ after being retrieved from the brink of death, defies imagination. The prediction of a person’s vegetative state in ICU inevitably leads to the possibility of organ harvesting. Thus, Dell’s Being, as she perceived, was reduced to a blade of “grass.” In his aptly titled literary work, The Lazarus Case, John Lantos appealed to people in this situation to embrace uncertainty, to expect and to tolerate a range of outcomes (Lantos, 2001). However, neither organ donation nor transplantation was part of Dell’s moral value.

I would never have a heart transplant. I know that. (…) The heart is … I know it is a very old fashioned view but I believe that is where your soul is. That is where you feel things. That is what makes you, you … is in your heart. I don’t want to lose that. I am not prepared to lose that. You know, I am happy, I am dying, it is not scary. I’d much rather not have one [ICD] and die.

It was Dell’s worldview that others should not be permitted to control her living and her dying. Dell valued sudden cardiac death as a good death (Evans & Walsh, 2002). Having control over the circumstances of her death meant that she would choose her own dying trajectory. Implantation with an ICD meant Dell was controlled on the brink of life and death indefinitely and that she was unable to “go gently in that good night [death]” (Ackerman, 1997, p. 314).

In contrast to Hugh and Dell, Jade attended transplant clinic while her life was sustained by implantation of her heart with an ICD. Jade had lost both small daughters to sudden cardiac death at a time when children were not considered for implantation. Jade’s heart and her daughters were synonymous in meaning to her and she wanted her heart to continue beating as a gift of life for them. Jade captured her experience in its entirety. Jades’ situation was a constant ebb and flow between life and death.

The physical feeling having a dirty great hole in my insides that can only be filled by their Being, seems to be growing. My heart is still breaking painfully and yearning for my babies. It has been like having my heart cut out and being told to go on living.

After Jock experienced a sudden cardiac arrest, he believed that he had been given yet a further chance at living. Jock had been dying twice before, pre-implantation. Implantation of his heart with an ICD was like a third life yet he knew he lived each day between life and death.
I can remember being in the ambulance and someone calling me. I have vague recollections, sort of flashes. I probably consider this [survival] … I guess this is being silly but I think this is like my third life sort of thing. Before I got my valve replacement I was going down hill very fast. I could feel myself slowly sleeping more and more. I was just lying there going to sleep, I did not have any energy. I am not looking forward to a discharge from my defibrillator. I think that will probably happen seeing it has been so close several times. IT IS ONLY A MATTER OF TIME.

In Jock’s reflection he re-opens his past, present and future experiences of living between life and death. In this way Jock was recalling the notion of his own transience-in-the-world. At one point in time Jock had been moving ever closer toward the end of life and death rather than existing between. His “slowly sleeping more and more” represented his past closeness to death; implantation of his heart with the ICD represented his present retrieval from death; and his conviction of a future “matter of time” represented further closeness toward living between life and death.

IMPLANTATION AS BODY-TEMPORALITY/TIME

Time is not a sequence of “external events” or “internal states” but rather, a chain of interlocking “fields of presence” (Langer, 1989, p. 128; Merleau-Ponty, 1962). Fields of presence implicate heart implantation in space and time: “things co-exist in space because they are present to the same perceiving subject and enveloped in one and the same temporal wave” (Merleau-Ponty, 1962, p. 275). In recipients’ dialogue there are many references to time in many different contexts. Their dialogue follows a temporal mapping of their lived experiences with heart implantation with a permanent ICD. Simon experienced the tension of time when he was flown from a regional area.

It’s like being on stage or whatever. It’s just everyone watching you. It’s like you are sitting there and you know everyone is watching you. The people around you are freaking out. What is he going to do and that sort of thing, I guess. They were waiting for something to happen … for me to explode or something.

As the human observer Simon experienced the “anxiety” of others’ expectations as a performer on stage. With the tension of passing time and the potential of some event, Simon was sensitive to the atmosphere he described as “freaking out.” For Simon, time and implantation with the ICD were closely linked.
After I got all the shocks I did not want it [ICD] anymore. But, yeah, I put a fair bit of blame in it. That’s because it was the cause of everything. But it wasn’t going to go anywhere … they said, “you have to wait.” So I sort of … I’ll look after you [ICD] and not do anything that is going to upset you and you look after me. Don’t electrocute too many times. I guess at the start I did not want it. I didn’t believe that it was there a lot of the time, so I just went away and said, “bugger it.” I guess for a while I thought I would rather lose my arm than have this [ICD].

Examination of Simon’s dialogue demonstrates how time infiltrated his life-world. For example, “after; anymore; wait; too many times; start; a lot of the time; while.” Simon’s attempts at negotiation were futile because of the permanence of the ICD. This state of permanence overrode his subjectivity, which was shaped by temporality/time. In making a covenant with the ICD, Simon’s intention was to bide his time. At this point in time, the cyclic time of heart implantation was bound in “the perpetual reiteration of the sequence of past, present and future” (Merleau-Ponty, 1962, p. 453).

When time stood still

Many people who experience implantation of their hearts and bodies with an ICD are victims of sudden cardiac death. ‘Sudden,’ ‘suddenly,’ ‘all of a sudden,’ are expressions that draw the attention to a specific time. An episode of sudden cardiac death is, for the person, an experience of when time stood still. For some participants in this study time stood still when they ceased to remember what happened to them over a period of time. They lost time. Stan was one such participant.

I can’t remember. I can’t remember anything from ah, about when they woke me up. After that I remember being woken up and then about three days later in the heart ward. The only thing I can remember about that is I was lying on a bed that was going backwards and forwards all the time. Apparently the ward was full and I was in a bed that was in the way. So to get around me they had to move my bed all the time. All the tests that they did they could not find any … no heart problems. They don’t know what happened. So they set it up, put in an ICD and said, “see you later.” So that is it. That is the end of my life.

When time began to mean something to Stan it took the form of his body being in a hospital bed that was continually being shifted. The concept of time to Stan in his experience of implantation meant a loss of part of his life, feeling dislocated in an unknown place, not knowing the reason for heart implantation and being dismissed until later in time. As in all experiences of temporality Stan experienced what it meant to
come to the end. He felt his life ended with implantation of his heart with the ICD yet the permanency of the ICD remained.

Jock’s experience of sudden cardiac death, loss of memory and time standing still, was similar yet different.

All I can recall is getting off the bus. Next thing I remember is being in hospital. This was four days later. I was asking what had happened, where I was, and what have you? Apparently people were talking to me during that period. I was asking questions. Where am I, what am I doing here? I was asking those questions for four or five days. I woke up and my son had been in quite often to see me. He got tired of me asking these questions even though my eyes were closed. So he wrote all the answers down, four or five pages, of all the questions I was asking. When I opened my eyes he said, “these are the questions you have been asking for the last four or five days.” I read the questions and said, “Is that what happened?”

Lost time through memory loss was traumatic for victims of sudden cardiac death in this study. This condition distorted the sense of self these people had previously known. The many questions asked by these people signified the fragmentation of past whole-selves into uncertain part-selves that emerged from the trauma of lost time (Young, 1996). Dell’s experience of time standing still was very different in the time period prior to and after heart implantation.

I had a sudden cardiac death when I was swimming in a carnival competition. I actually had an after death experience, when I was in the ambulance going to the hospital. It was not scary at all. It was quite pleasant, so I was never scared of dying. I can remember it clearly as if it were yesterday. I was lying in the back of the ambulance. Dad was leaning over me, praying. And suddenly I was out of my body. I was looking down on top of his head. I could see very clearly the back of his head and my body lying there. The top of the ambulance was not there any more. Nothing was solid. I was heading up towards a light. It was not so much a dark tunnel, it was just dark, but quite wide and there was a light up there. I was heading up there and I kept thinking like, I can’t go yet. Then I opened my eyes and I was back to my body. It was not scary, and it was just like having no arms, but I was still me.

Dell experienced Ars Moriendo, preparing to die, as she became engulfed in the solidity of life and the liquidity of near death. Her surroundings became a matrix of liquid form in preparation for her person to pass through. Dell experienced temporality in all its complexity and certainty. Dell’s connection to her father appeared to be a significant force in her out of body experience and may have been the influence whereby she was able to resist the magnetism of the upward light. However, the peace of spirit Dell
experienced was not such that she was unaware of herself as a Being. Dell felt reunited with her body with an understanding that there was nothing to fear about inevitable mortality. After a second sudden cardiac death episode followed by heart implantation Dell’s Being was robbed of its previous peace.

My memory is not nearly as good as it was. I had such a great memory. I keep notes on everything. I write everything down. I held down a full time position while I had my short-term memory loss. It was shocking. I had to keep asking the password everyday. I could never remember it. I’d always write things down at the end of each day. I could not remember any more. It was particularly details. Like what time is such and such coming in. I’d have to refer to my notes. At its most extreme, I feel like a person who has very poor vision and is in a dark room trying to feel around. I am not quite sure where I have put things or where I will find things, or what is going to happen next.

Time was of the utmost importance to Dell as she struggled with everyday living post implantation. There was only temporality in Dell’s life without the ability to remember what should come next and what she had been informed of beforehand. This type of uncertainty was like Riesman’s (1954) concept of secret marginality coined prior to van Gennep’s concept of liminality (1960). Dell was unable to identify with temporality and felt compelled to function on the margins of secrecy. Attempts to veil memory loss and attempts to conquer temporality created much despair and lost time for Dell. The permanency of heart implantation exacerbated the torment of temporality in relation to lost memory and the reality of lost identity.

I’d get lost on the way home from work. I could not find my way home. I would get on a bus and I’d end up way over the other side of town when I was trying to get somewhere else. I just could not remember what I was doing or where I was going or anything. I think in a way that was my body trying to protect myself from things that I really didn’t want to know about. Otherwise, it drove me crazy. I hate that. People know things that I have done, and I don’t.

Reflection on implantation brought images to consciousness and for recipients, time stood still in the image. Such was the case with the photograph in this thesis. It represents a time in May’s biography when time was captured and held fast for all time; “time stands still; there is no time, there are only images” (Lightman, 1994, p. 75). May felt time stand still when the cardiologist informed her “it is time to go under the knife.” For May “the time has come that we always knew would come.”

Recipients were not the same people they had once been, either in everyday life or within the liminality of hybrid bodies. All were trying to “find my way home.”
previously mentioned all wandered betwixt and between a time warp, in the wasteland of liminality where their intentions to ‘arrive’ were thwarted by the stillness of time. Dell sort solace in rationalising that the body in its hybrid form offered some protection from the lostness and stillness of time she was unable to understand or accept. All recipients agreed that too much time dwelling on implantation of their bodies with an ICD reduced them to being “crazy,” “twisted,” “angry,” “freaky,” and “depressed.” The recipients with memory loss no longer knew who or what they had become in the liminality of implantation. The stillness of time had stolen their sense of self. They were forced to ask, “Who am I?” “What am I?” “What has happened to me?” “Where am I?” Other people knew some of the answers but recipients “hated” not having experienced their own body in a time of crisis when time appears to stand still. Not knowing disembodied their Being with “anger,” “frustration,” “embarrassment,” “fear,” and “loss.” The nature of “time is a nightingale, fluttering and flying, pursued by those who would stop time in a bell jar” (Lightman, 1994, p. 172).

When time went racing by

In contrast to time standing still, some participants experienced another modality of temporality as their heartbeat began “racing.” “I know I am in danger and there is a need to rectify the situation promptly. I know 300 beats is a very serious situation” (Jay). The perception of time racing by has been described as “my present may cease to be a factual present quickly carried away and abolished by the flow of duration” (Merleau-Ponty, 1962, p. 69). Dell described the racing heartbeat as a “metronome” out of control. Jay understood his “chest discomfort” as “my heartbeat was about 300 bpm.” Noel also experienced “Um, it [heart] went up to 300 beats per minute (bpm).” Jay entered into temporality in terms of his pre-implanted body when his heartbeat raced uncontrollably and caused him “pain.” Jay reflected on his original heart arrhythmia, “I can remember saying to the cardiologist … I don’t want to die! And I guess that is still with me.”

What can be understood in terms of time racing by and an arrhythmic heart rate of 300 bpm? The healthy heart rate in sinus rhythm is considered to be within 60-100 bpm (Tortora, 2003). How long can a person’s life be sustained by a heart rate of 300 bpm? With each arrhythmic heartbeat a person’s perception of time becomes exaggerated in
the immediacy of time racing by. Jay realised his time was racing by each time he experienced a cardiac episode.

I experienced some central chest pain, at home, and um, I tried three anginine tablets. I still had persistent strong pain (...) gradually I had more episodes of VT (ventricular tachycardia). They became more and more frequent. First, six months, then three months and six weeks and then six days, sort of thing. My cardiologist recommended that I seriously consider having an ICD implant. I resisted that for quite some time.

Temporality becomes personified for the person who is aware that “time’s winged chariot” (Wyschogrod, 1973, p. 6) places a time limit on the lifespan. During this time under the shadow of living or dying the person struggles with philosophical questions such as posed by Kant (1955): What can I know? What ought I to do? What may I hope? Jay was given warning of time’s winged chariot over a period of time where he knew his racing heart might sustain him for an instant or an indefinable time. Yet he resisted heart implantation. Heidegger (1968) has suggested that a person’s life validity, in the face of mortality, may be more an extension of personal values than an extension in time. While Jay resisted the possibility of life extension through implantation with an ICD, there was opportunity for him to evaluate what his life meant in the present and what his life would mean in the future. This time of resistance for Jay may have been a time when he struggled with Kantian questions such as; how quickly would time pass? How much time, would passing time allow him? What might he hope for in agreeing to heart implantation when his cardiologist “had his reservations?”

The timing of implantation for Noel evoked a time of questioning. “When I saw a cardiologist he was recommending me to have the ICD put in a few months after I was married.” Implantation at this time of beginning a new life caused “devastation,” “fear,” “anxiety,” “loss of peace of mind,” loss of intimacy for a period of time, loss of plans and dreams, and “changes as to what I did and did not do.” Implantation evoked the questions: What would he do? At what time would he decide? How would his new wife feel about his situation?

In the race of time epitomised by the racing heartbeat Simon did not have the opportunity to resist what would happen to his body.
He [doctor] went to feel for a pulse (…) and started hooking me up to machines and things. I didn’t really know what was going on and the machine was making this beeping. Just beep, beep, beep, and I thought it was some alarm or something and asked him if he was going to turn it off. They said, “no, that’s your heart.” Apparently I was doing about 300 beats per minute.

Throughout the history of medicine, the “secret idiom” of the pulse has been claimed as nature’s way of speaking to the practitioner – the pulse described as the “language of life” (Kuriyama, 1999, p. 20). Simon’s racing pulse meant an immediate turn of attention to machines and bioelectronics. Even so, because of his profession, Simon knew an “alarm” meant that time was of the essence; time can get away when action is delayed; “And by the fastness of our pace, Eternity draws near” (Metcalfe, 1961). In contrast to Jay, Simon had no knowledge of heart arrhythmia or indeed what was happening to his body. Once again there was evidence of a person becoming lost in a liminal-relation as to “what was going on” with his/her body in the words “I didn’t have a clue.” Simon thought “I might have cracked a rib,” and “I might have been dehydrated.” Simon’s temporality raced by in the form of a metronome-like “beep” as the “machines” went into alarm mode. In the words of Buber (1965, p. 130) “a force [300bpm] bore me toward dying, and its flight [racing] I called time.” As a consequence of Simon’s racing heartbeat, the possibility of dying and subsequent numerous shocks from the ICD, he felt compelled to know at all times the rhythm of his pulse. Implantation was synonymous with “machines,” “leaning on it,” “frightened,” “alarming” and “freak out.”

I’ve got this little pulse monitor thing that worked off my finger. I was leaning on it like it was some sort of comfort thing. I’m just constantly aware of it and frightened of it, you know. If I was using this heart monitor and it was beeping funny, I would freak out as well, and that sort of thing.

Simon’s preoccupation with timing his racing pulse speaks of flashbacks to the first time his heartbeat raced at 300bpm. Even though there was no chance to escape the invisible arrhythmic heartbeat Simon needed some visible and audible warning that an arrhythmic episode was immanent. In the trauma of the initial episode Simon did not know what was happening to his body. With the beep of the pulse monitor, even amidst the terror the sound precipitated, Simon knew for a few seconds in time what his body would experience. Lived temporality was disembodied because terror accompanied implantation.
IMPLANTATION AS BODY-SPATIALITY/MOVEMENT

There is a reciprocal connection between the body and its immediate surroundings within the world. Things or objects around the body or, in the case of implantation, within the body, are self-evident because of the body’s connection with space and things-in-the-world (Merleau-Ponty, 1962). Within the body’s physicality there is no double-intentionality that allows for an object, such as the ICD, to be accommodated. In the process of procreation the female uterus, merely centimetres in dormant size (Bergum, 1989), is only a temporary ‘nest’ for a fetus who grows to perhaps ten times the size of the uterus. Even so, the body is prepared for this process. By contrast, implantation of the body with a permanent ICD unit is forced within an artificially created space. “It is not supposed to be there. It was never intended to be there” (May), and “It is not a natural treatment. It is not replicating anything in nature that nature can do to my heart. There is nothing natural about it” (Noel).

Implantation follows a process that invades delicate and valued body spaces. The electronic leads, as part of the permanently implanted ICD, intrude into and invade the space of critical veins, the primary purpose of which is to carry life-sustaining blood to the body. Space within the heart is intended for the flow of life-sustaining blood, yet electrodes penetrate a place held as special by eight of those in this study whose hearts and bodies are the sites of implantation with an ICD. Each expressed his/her perspective on what the heart meant on a personal level. The heart is “more than just an organ,” (Noel); “the centre point of life,” (Hugh); “my second life,” (Stan); “my third life,” (Jock); “the central part of me [is] inside my heart,” (Dell); “I am very sensitive to my heart,” (Simon); “I don’t like the idea of having something implanted there,” (Jay); “your heart is pure, your soul is free,” (Jade).

In contrast to the other eight recipients May’s metaphors in relation to her heart and body spaces held angst. “To me it is a necessary evil to keep me alive and if a transplant wasn’t so risky I would happily wave goodbye to this model and trade up.” Resentment abounds in May’s perspective. When nature fails to meet body-space expectations human subjectivity can be affected in numerous ways and extremely complex ways. For May, neither implantation of heart-space, nor transplantation of heart-space, was an acceptable solution for nature’s failure. Although ICD technology
did not exist in Shakespeare’s space in time, his views on the heart add meaning to implantation with electrodes - “these burs are in my heart” (Shakespeare, 1978), and with the ICD, “there is no remedy, it [ICD] is so grounded inward in my heart” (Muir, 1979). The heart, held as perhaps the most subjective part of Being, was not the only revered space for a person’s being-in-the-world. Special spaces, such as home and places of worship are revered in significant ways.

**Being disembodied within special spaces**

As an object with a programmed function, the implanted ICD was not acceptable by recipients in the subjectivity of revered spaces, such as church, home, the outdoors, the sports field, the shopping centre, or any other space that belongs to the social dimension of Being. The ICD follows its cybernetic program regardless of our cultural perception of special spaces. Noel and Jay were visibly affected when they related their experience in church.

I was giving a talk at church … and it [ICD] decided to go off and keep going off. It [ICD] went off 5-6 times. It is like … it is a bit uncomfortable talking about it, but I can deal with it. It is an incredibly freaky experience. I did not want it. I did not want something in my chest that could do something like that. I never felt the pacing that they said would happen. Why it would go off. Just, WHACK, no notice. WHACK, and the next thing … on the ground. When it fired off all those times in a row, that was the worst experience I have ever felt (Noel).

And:

I only had it [ICD] about ten weeks and I had um, … I had been reading at church. As I went back to my place, I had a slight shudder. So that was a bit embarrassing. Some people noticed it. I subsequently made a decision to resign myself from that particular job … it was something I enjoyed doing. To make that decision was a significant thing … (Jay).

There was deep betrayal on many levels in Noel’s disembodied experience. Flashback caused visible anxiety, as implantation betrayal was perceived as an experience not to be believed unless it was lived through. There was no sanctuary in church spatiality when “it” [ICD] discharged and continued to “whack” without warning while Noel was defenceless “on the ground.” There is dissociation in not naming the ICD and rejection in not wanting implantation of “some-thing.” It was not possible for Noel to understand this surreal betrayal because it reduced his body to “extreme passivity, impotence,
abandonment and solitude” (Levinas, 1988, p. 158). The essence of implantation epitomised the “worst” of anything that could happen in Noel’s life.

The meaning of Noel and Jay’s experience lies within what drew them into the space that is church. All, but atheists, believe that within church there is hallowed space that extends peace of spirit, renewal of inner self and transcendence over personal dilemmas (Jureidini, Kenny & Poole, 1997). Jay elaborated on what church space meant.

It is a sacred place, a place that has been blessed. (…) It has a different atmosphere. It is a place that is quiet and peaceful and restful. There is a sense of respect. It is a place where I am comfortable and safe.

Their intention was to give testimony to their belief in the hallowed space and to the power within that space that is omnipotent above all human Being. Both men realised for the first time that implantation of their heart and body meant they would not be spared “embarrassing” and “incredibly freaky” “whacks” no matter what space their bodies moved within. In the moment of realisation, when Noel and Jay experienced disembodiment by the ICD, the meaning of implantation became associated with bioelectronic “whacks” where church spatiality was altered; “the phantoms of internal experience are possible only as things borrowed from external experience” (Merleau-Ponty, 1962, p. 27). Speaking in public to a congregation of peers is an act of faith in personal self-efficacy and belief in peerage acceptance. Implantation of the heart with an ICD showed itself as capable of destroying the values of faith and belief when, in terms of movement through space with confidence, neither Noel nor Jay again actively participated in church. Noel elaborated.

It gave me a pummelling. I did not have any [confidence] left. It was a while before I could go back to church. I wanted to go. But being in the place where I was knocked to the ground by the treatment made me re-live it. I would just sit outside and stuff. It has been two years since … I am still (…) apprehensive, and I always make sure I take extra medication.

Being outside church spatiality resulted in some liberation from re-living body trauma that is implantation. However, even the passage of time could not dim the memory of “a pummelling” and the association continued to cause flashback anxiety. Noel turned to the only possibility that might enable his re-entry into part of his lived-world; “extra medication.” Oliver Sacks (1986, p. 144) wrote of self-trauma when his leg remained neurologically impaired for a time after surgery. In his horror Sacks could not accept
his paralysed leg as belonging to himself. Eventually Sacks was to be discharged home but his “fear of re-entry” into-the-world bordered on terror. His terror stemmed from re-entering a world that did not understand and could not imagine his self-trauma. His previous world of people saw him only in the situation they themselves never wanted to be. He recoiled from re-entering the space where self-trauma had occurred.

**Being inside-in-the-world**

Human beings look upon their homes as “protection that is closest to us, a protection adapted to our bodies” (Bachelard, 1994, p. 101). Furthermore, home is the space created in our imagination as to what represents a haven when we are troubled, a resting place when we are weary and our intimate corner-of-the-world. Our home expresses what we experience inside. As with human body-space, Bachelard captured this ‘inside’ experience by drawing on Jules Michelet’s image of the relationship between a bird and its nest; “The house is a bird’s very person; it is its form and its most immediate effort (…) pressed on countless times by the bird’s breast, its heart, surely with difficulty in breathing, perhaps even, with palpitations.” [cited p. 11).

Jay spoke about his home like it was part of his very person. He spoke of implantation and the ICD as the dissociated “it” as did all recipients in this study. Experiences of specific spaces in the home strike a knowing chord when intimate meanings lift the seemingly insignificant to significant. Sensitivities are awakened when we feel that experiences in the home could have been our own. Jay spoke of what home-space meant.

I can relax and feel safe (…) my privacy is not invaded. For the most part I feel safe. I say for the most part because there are occasions when I have lost confidence after receiving a shock from my ICD and am nervous about being in the house by myself. I avoid having a shower if my wife is not home.

Implantation brings ambiguity into the safe-space that is the very personification of being human. The ICD represents invasion, loss of confidence, nervousness and avoidance in a space created for “control,” “latitude,” “privacy,” and knowing. The privacy image of my own bathroom is invaded when I reflect on Jay’s account of “it [ICD] hit me as I was cleaning my teeth.” Implantation meant that Jay would never
know when his safe-space would lose its intended safeness. The bathroom featured in Jade’s experience of feeling “horrible.”

Yeah, I was just standing in the bathroom and all of a sudden … I felt queasy and shaky, um, felt sick, had a bit of chest tightness. Being a cardiac nurse you would know about the thing where people want to go to the toilet and open their bowels just before they die. I felt like going to the toilet and I (…) no, no way am I going to the toilet at this moment in my life.

Every day body-attention, such as teeth cleaning and toileting are usually taken-for-granted and barely warrant a passing thought in our consciousness. Yet, when the heart is the site of implantation, wherever the body is located in spatiality, the ordinary can suddenly become the extraordinary; intimacy be violated; and living replaced by mortality. Recipients learned that there was no space-in-the-world where the implanted body moved without the possibility of the ICD making its presence known.

The essence of implantation would make itself known to Jay in other everyday casual activities, such as talking socially; “It hit me again the next day, about one o’clock in the morning.” Even in sleep Jay’s comfort and security was jeopardised with recurring episodes; “it fired again at four twenty in the morning. It woke me from sleep.” Another night was disturbed when “it fired again just after midnight. I had just gone to bed.” In the space and time when the organic body needs rejuvenating rest and sleep, the body-space hybridised by bioelectronics responds to cybernetic needs alone. Such is the nature of heart and body implantation with an ICD. Special celebrations when people prefer to be within the intimate and significant space of home were not exempt from the invasive presence that is implantation; “the device fired at our (…) wedding anniversary, the device fired while I was giving a speech” (Jay).

Bachelard (1994) draws attention to the house-test used by psychologists in determining a child’s perception of home space. The spontaneity of a child’s drawing often illustrates what lies within the spatiality of home. If the child is happy the illustrated perception of the house may be strong, broad and open in form. The image may display bright colours, flowers, windows, a door and warm smoke curling into a blue sky. Conversely, the troubled child may illustrate the kinetic features of home spatiality as
narrow and dark; a space not inviting to live within. The house-test indicates the depth of intimacy between people and their homes and the significance of safe-space.

Earlier in this chapter I reported Dell and May speaking of images. Both felt that there was no safe spatiality in their homes. Similar to Jay and Jade’s experience, the bathroom featured as the space where the vulnerable body was exposed to the nature of implantation.

It [ICD] was horrible. I got really good at looking totally at my eyes in the mirror. I just wouldn’t look at the rest of me at all. (...) I knew it [ICD] was going to go off and just hit me. I didn’t know what to expect. I didn’t know how it was going to feel. I just didn’t know how it was all going to be. (Dell).

The horror of body-implantation was so vivid to Dell and other recipients that avoidance and dissociation in not looking at, or acknowledging the device, was a defence mechanism born of desperation to avoid “it going off.” Recipients were convinced that the ICD was “waiting to take me down.” The most famous of all shower images of horror is Alfred Hitchcock’s portrayal of the shower scene in his film Psycho (Hitchcock, 1960). Hitchcock immortalised the vulnerability of the naked female body behind the shower curtain. May physically absorbed the epitome of horror genre. May’s house-test would surely have been an image of terror where she could not bear to be alone in menacing spatiality.

In the shower, as soon as I would take off a bra, in the shower I guess with the extra weight of my breast, it [ICD] would begin twitching – AND IT WAS DISGUSTING. Moving on its own accord it was scary. I called my sister and said, “can you come and stay with me?” I was scared. Oh, it was disgusting, revolting [nervous laugh]. I could feel it, physically absorb it, the jumping and moving, yeah, it was disgusting.

May experienced the physical significance of the ICD’s capacity to twitch, jump and move, and this manifestation of body-implantation revolted and disgusted her. In this way May experienced disembodiment as “horrible.” Hoped for safety in recipients’ homes eluded them, with the only option being a call for help and comfort from family members.
Being outside-in-the-world

Implantation is what it implies; it is always within the heart and body, no matter where the body moves within space-in-the-world. In discussing the dialectics of inside and outside Bachelard (1994, p. 218) states, “Here fear is being itself. Where can one flee, where find refuge? In what shelter can one take refuge? Space is nothing but a horrible outside-inside.” While there was no refuge from implantation for Jay inside his own home, his experience outside his home was, as one pursued by fear itself.

I was walking along the street and I got the thing. The thing hit me, and knocked me on the grass. When you receive a shock … you lose all your self-confidence. You’ve almost got to start again and literally pick yourself up off the ground and get going … very tentatively. Just thinking, will it fire again, will it go again, will it fire again, will I get home? Um, go and lay down … you think, if I just get through this next hour.

This “thing” that Jay speaks of with such questioning fear and trepidation, is it fear itself in the form of the implanted ICD, or is it fear of death? In our Western culture that is death-defying (Lock, 2002), death in the public space of the street is the ultimate humiliation. Already humiliated and devoid of “self-confidence” Jay’s mind filled with questions and the lure of being home. The thought of surviving “this next hour” may be an enterprise in permanence to expand “temporal and spatial boundaries of being, with a view to dismantling them altogether” (Bauman, 1992, p. 5). Individual death is the only narrative that can never be told thereby remaining unspeakable (Merleau-Ponty, 1962). Yet implantation of the heart with an ICD was a constant reminder of the inevitability of mortality and the “transience of our being-in-the-world” which implantation seeks to deny (Bauman, 1992, p. 12).

Contrary to Jay’s efforts to deny mortality, Noel’s experience in church convinced him of the possibility of his death to a depth where he said “goodbye” to his wife. With survival came the fear of outside spatiality, which Noel tried to avoid.

After it firing off and everything when I was not doing anything strenuous you know, I was under stress. It was not even safe for me to walk around in public places. … Shopping centres, places like that, without thinking well, can it go off here? (…) Because it is so sudden, it does not take long to hit the ground. Then when it does it again, it is like, why is it doing it again? Why doesn’t it stop? Why did not it fix it the first time? Then you get worried. You could not switch it off.
Noel’s questioning fear is similar yet different to Jay’s experience in that Noel was fearful in the very thought of being within outside spatiality. Perhaps Noel’s fear was a combination of agoraphobic fear and fear of facing mortality. In the first instance Noel speaks of “public places” yet goes on to conclude that he “could not switch it off.” There is a breakdown of the boundary between inside-self and outside-space that is disembodying. In Merleau-Ponty’s (1962, p. 215) words, “every sensation carries within it the germ of a dream or depersonalisation (…) this activity takes place on the periphery of my being.” In other words our living and dying is “pre-personal horizons” that causes anxiety to our Being as “already born” and “still alive” because nothing can be done to alter those horizons (Merleau-Ponty, 1962, p. 216). However, this is what implantation is about; the attempts of bio electronic science to alter the horizons of life and death with natural demise being pushed further into the distance.

In agoraphobic fear, Noel wanted to avoid the public sensation of his shocked body and the ICD implantation that he was unable to switch off. Examining spatial distortions and extreme states of consciousness, such as primal, agoraphobic fear, Merleau-Ponty (1962, p. 216) discussed sensations over which we have no control.

Between my sensation and myself there stands always the thickness of some
primal acquisition, which prevents my experience from being clear of itself. I experience the sensation as a modality of a general existence, one already destined for a physical world and which runs through me without my being the cause of it.

Merleau-Ponty’s words could be applied to disembodied implantation when the ICD triggers fear as a primal acquisition. Primal fear takes control of sensation and self, thereby altering personal experience through bioelectronic shock. In this way, fear of bioelectronic shock is a liminal space of Being-in-the-world. Electricity was intended for the space of the object-world, yet as Simon experienced, “they started telling me they were going to electrocute me.”

Simon’s experience was similar yet different within a public space. The public experience of the nature of implantation was different in that Simon was compelled to shout his body-self dismay. The manifestation of dismayed body-self is always a problem of disembodiment. Whether the dismay is evident in a barely perceptible
cringe or a public spectacle of “freaking out,” a person is unable to embody the shock of sudden pain and body-self dismay.

We were in a shopping centre in England and it [ICD] really went off. I shouted, freaking out. All of a sudden the carpet is pulled out from under you and its from one end of the spectrum right down to the other and I couldn’t do anything.

Jay related his body response as a problem of action. To act within a body dilemma is not always within the range, or within the “spectrum” of socially acceptable responses. There are so many dichotomies on the continuum of descriptors when the body-self is powerless against slipping from “one end to the other.”

I was hurrying along the platform and just got into the train, and the device fired. I remember, I can still remember yelling out. There were a couple of young teenage girls, probably 14 or something in the seat behind me. I was conscious of them there. I turned around and said, “Oh, its just my defibrillator firing.” I thought how ridiculous that must have sounded to the kids. What the hell, they must have … this silly old man, what the hell is a defibrillator? I felt that I had to apologise or explain what had happened.

On the continuum of descriptors that may capture an involuntary “yelling out” in shock and pain while on public transport in close proximity to teenage girls, Jay chose “ridiculous and silly.” He also blamed himself for his situation and attempted to normalise what our culture regards as deviant behaviour. Frank (1991) questioned the body-work chronically ill people attempt in order to meet the expectations of society. In a culture fascinated by the ‘perfect physique’ the chronically ill represent the unacceptable. Jay labelled his body-self as a “silly old man” because he perceived he had drawn attention to his body-problem, thereby overstepping the barrier between healthy bodies and his implanted body. No matter how everyday his activity, Jay continued to be subjected to “significant pain” from bioelectronic shock that is heart implantation with an ICD. There was no refuge-in-the-world.

In the front yard of my home, I had been doing a little bit of weeding and the device hit me and knocked me on the ground. This was a real thump. Then it [ICD] hit me again. I stayed for quite some time.

All recipients learned that they could only function within the parameters of heart implantation. Post-implantation the relationship between body and ICD became one of servant and master. Once knocked to the ground Jay knew he dare not challenge being
“trapped inside an alien body” (Leder, 1990, p. 3). On the ground Jay had no freedom of spatiality. The public spatiality of the street was of particular concern.

It [ICD] hit me while I was driving the car. Then a second time about 30 seconds later. I can remember yelling out and I thought one of the neighbours might have heard me, but I was conscious of the fact that I had yelled out with the pain. Then it hit me a third time. I thought if it continues to um, fire, I’ll ring an ambulance (Jay).

Jay expressed a hermeneutic perspective of street spatiality as a person whose heart and body was implanted with an ICD. Moreover, his expression was as a person whose safety, identity and humanity was at risk.

In the street there is a certain threat to personal safety whereby I think about where I am and where I am going and how I am going to get there. Passers by could be a threat and so there is little verbal or eye contact or personal encounter. One remains anonymous … perhaps just a number or in the way of someone in a hurry. If I collapsed on the street I would hope that someone would come to my aid and so I have a medic alert bracelet and a mobile phone with me. I avoid being out by myself after dark. I keep my wife informed of my plans and movements.

Jay’s account of movement in the outside world of street spatiality was a vivid journey through vulnerability. It was a journey of confronting potential threat and consciously planning the journey as an explorer would plan entry into hostile territory. Potential threat may be avoided if Jay drew no attention outside-in-the-world. He planned to be anonymous in a way that would not stir his implanted heart and subsequently keep the ICD undisturbed. All recipients in this study were aware of their vulnerability and relied on strategies similar to Jay to increase the likelihood of remaining anonymous in outside-space. An additional strategy was to wear a heart monitor in the hope of gaining a few seconds in which to thwart the ICD shock. Jay’s account reads like a Stephen King novel in which the principal character moves along a vividly described street, always attempting to keep one step ahead of a perpetrating entity. Jay’s imagery was vivid.

After each shock, literally getting up on your feet and starting all over again … that is the best description of it because literally I have been on the footpath … I’ve been down on the ground, and I have had to get up on my knees and then get up … stand up and then gradually walk a few feet and all the time you have this feeling of what if? Or when? Or where would I be?
The unknowingness of vulnerability personified by the ICD’s capacity to strike down recipients at any time, in any space, was the undeserved nemesis that is implantation. Jay continued his hermeneutic journey through overbearing city-space.

And I found myself in the city walking close … not too close to the kerb … but walking close to the building alignment in case I did stumble or fall, I would perhaps catch something on the way down. These things were in my mind.

This image of Jay’s movement through spatiality outside-in-the-world portrayed the experience of most of the recipients in this study. There was physical danger and the emotionality of fear in being “too close” to spaces that go unnoticed by the general population. Because of heart implantation with an ICD it was necessary for recipients to move in spatiality that “perhaps” provided a chance for safety “on the way down.” In this way recipients were constantly alert for the undeserved nemesis within their body-space. Undeserved body-nemesis was interpreted by Simon as a body-punishment during activity. “It just blew my confidence because they couldn’t justify getting them [shocks]. What did I get them for? What are you punishing me for I didn’t do anything [wrong]?”

**IMPLANTATION AS BODY-EMOTIONALITY**

Emotionality is the experience of self-feeling in response to a person’s emotive circumstance (Pearsall & Hanks, 2001). The essential structures of emotionality assist with understanding how recipients could feel within a matrix of emotional responses, when their hearts and bodies were implanted with an ICD. Stanislavski (1936, p. 158) could have been offering meaning on recipients’ implantation circumstance in his philosophy on emotion.

A lived, believed-in, situated, temporally embodied experience that radiates through a person's stream of consciousness, is felt in and runs through his body, and in the process of being lived, plunges the person in a wholly new and transformed reality - the reality of a world that is being constituted by the emotional experience.

Amidst the obvious grief, the nervous laugh and the holding back of tears during her dialogue, Jade volunteered a hermeneutic explanation of her emotionality.
I switch into a very neutral … coping mode. I don’t get all emotional and weepy and teary and things like that. (…) About three months later I’ll come down in a screaming heap. But I um, … sort of like switching off. That is just my inbuilt, natural response. (…) I honestly don’t remember how I felt because I was in remote control.

Jade’s lack of immediate emotional response to tragedy and her mortality is an example of blocked consciousness. Shock and numbness prevent the flow of reality into a person’s stream of consciousness. As Jade explained, when consciousness clears, the world of reality becomes one of intense emotionality or “a screaming heap.” Conversely, Jade was able at a point in her dialogue to describe her “broken heart” as “emptiness [nervous laugh]. I can’t put it any other way but an unfillable emptiness. You are utterly, totally despondent. It can’t be fixed.” Noel also felt the emptiness of loss.

Um, it was a process I went through. Like, the usual things, denial, anger, disbelief, depression … more than depression really, it was the loss of not being able to do the things I love the most.

These recipients expressed the emotionality of feeling the emptiness of loss, yet while they have feelings in common, these feelings can never be the same (Denzin, 1984). In other words the feelings are shared but the specific content of each feeling arises from the body-self of unique individuals. All recipients felt a loss that was universal, while each loss was singular in its meaning. Jade’s loss could not “be fixed” while Noel sought distraction.

Nothing would compare to what I went through. Nothing I could have experienced. No car accident I have been involved in would come close to relate to what it has caused me to feel … that effect. That is another thing I have to deal with as long as I have it [ICD] there, it will take time. As long as I have it [ICD] I will need to find things to distract me so I can cope with it.

Singular feelings of emotionality surfaced in the form of physical gesture. Throughout his dialogue Jay continually lifted his hand to his scalp. This gesture was more pronounced when there was difficulty in expression. Jay elaborated.

I still take medication. I take it in tandem with the device. [Drug] is a very powerful drug. Ultra violet light causes the drug to affect the skin. I wear long sleeve shirts and a hat whenever I go outdoors. Perhaps in an intense situation um, people have said, “gee, you are looking a bit purple today.” So that can be a discomfort.
The insensitivity of people appeared to evoke feelings of emotionality in Jay to the extent that he felt he wore the stamp of implantation. Embodied value-feelings, such as embarrassment or “discomfort” give meaning to the emotionality of stigma. Thus, these feelings are synonymous with stigma (Scheler, 1970, p.13). Jay spoke of feeling “conscious of it [ICD] everyday and probably every hour of the day.” In this situation where Jay’s stream of consciousness was full of the presence of the invisible ICD, it precipitated an emotive body-response that others were continually reminded of his situation because of a visible discoloration. Jay’s explanation enabled me to understand the liminal connection between his arrhythmia, implantation, the ICD, and the medication. This liminal connection was part of the essence of implantation. Similarly, Stan felt compelled to rub the site of implantation of his heart and body. Stan recounted that he was aware of the ICD.

Yeah, all the time (nervous laugh). Well, you just know its there. You feel it [ICD] there all the time. Sometimes, you know, you’ve got to give it a massage or whatever, you know. Sometimes there’s a bit of muscle, ah pain, which is … you know the feeling there, that lets you know its there. And sometimes it might slip on its side sort of, … you know its there too. Oh, irritation, I just know its there. I wouldn’t call it pain, I just know its there, and I suppose every now and then I’ve got to give it a bit of a rub to make it feel better …

Stan’s body-feeling of emotionality was evident in the physical rubbing of the implantation site and in the repetition of his dialogue. Feelings of confusion and uncertainty permeated Stan’s emotional persona. In his stream of consciousness Stan lived-through the emotionality of disbelief and bewilderment when the cardiologist “walked over to me and said, you’re stuffed.” Even though Stan could not acknowledge the ICD, except in a disembodied context of “it,” he was unable to dissociate from his feelings of rejection for the device. Disbelief was based on Stan’s scientific background and absence of evidence of cardiac dysfunction, “I’ve been told all fibs. I don’t believe it!” [skeptical laugh]. Stan’s persistent agitation in rubbing the implantation site was reminiscent of Dell’s desire to “rip it [ICD] out.” Deep anxiety flowed through all recipients’ dialogue in this study.

**Anxiety and fear: Like waking up into a nightmare**

The ability of the body to express emotionality takes “into account the emotional content of the word (…)”. It would then be found that the words (…) are so many ways
of ‘singing’ the world (...) because they extract, and literally express, their emotional essence” (Merleau-Ponty, 1962, p. 187). May had been aware, since childhood, of her lived-emotionality through her body-feelings. She agreed to walk through the gamut of embodied emotionality experienced over time.

As a young teenager May’s emotionality ebbed and flowed as her heart and body symptoms “progressively got worse (...) I was almost in a wheelchair.” Tiredness and chest tightness was “like a crushing, like an elephant standing on your chest. That was pretty severe.” Medications prevented “getting passionate about causes” and “affected my personality because I am not an emotional person.” Pre-implantation, May felt “I was pretty invincible. Then I realized it was not a piece of cake. Very scary.” As May’s heart dysfunction “got progressively worse quite quickly,” open-heart surgery was rescheduled and “that made it a bit more dramatic and made me feel more emotional.” Emotionality was bound up in walking up stairs “bent double and one at a time.” Missing out on the debutant ball and the school formal did not stir feelings of “guilt” or “resentment” because “tightening in the chest” and “a crushing feeling (...) was by far the worst.” Waking up from surgery, May was “scared (...) like waking up into a nightmare.” After removal of the urinary catheter, the physiotherapist walked May to the bathroom where she was instructed in a trial void. The invasiveness, anxiety and fear of the catheter forced May to claim success, “I lied because I did not want the catheter to be put back in.” Consequently, May “lay there panicking about what I’d done and whether I was going to be really, really sick.” No one mentioned that the body goes into shock after cardiac surgery. Thus, May’s emotionality became chaotic when menstruation and breast discharge was noted when May was “walking down the hall.” It “was pretty confronting” to look down and see “these two wet circles on my pyjamas.” With her body-response in shock, there was significant weight-loss, “I put the soap on my legs and it slipped through.” May expressed anxiety and fear.

Oh, I was shocked. (...) I could not believe that could happen. I remember sitting in the shower … looking at the scar and thinking, oh, look what they have done to me (...) they have done something drastic to my body. I thought something shocking has happened.

There was no sense of coherence in the lived-through, “shocking,” toxic events that brought anxiety and fear into May’s emotionality. Such toxic life events affect a person’s well being so as to shatter positive assumptions and beliefs about
being-in-the-world (Wortman, Silver, & Kessler, 1993). While people struggle to endure with embraced beliefs, sufficiently toxic life-events may induce negative emotionality. May continued with her dialogue, “My friends used to pretend to measure me up for the coffin, and they made me write a will, so they knew who would get my CDs. It was all our way of dealing with [it]. We never, ever discussed the fear.”

May spoke of the intensive care unit in terms of “the smell.” Emotionality was evident in the body-responses of tear-filled eyes and wiping her nose.

Anything that smells like what they had in that unit I can’t handle it. I can’t stand anything that smells of the particular shampoo that I was using at that time. They used to wash my hair. And the smell of the pink floor wash, you know what they use? The smell, it still has an emotional reaction for me. It just makes me so upset like I want to throw up. I suppose the memory of it all … a bad experience.

In many cases of traumatic experience, such as being in an intensive care unit, there exists a trigger that sets in motion a body-response to trauma-memory (Bowman, 1997). May’s trauma-memory was triggered by the sensation of smells that disturbed her body-emotionality to the point of physical reaction. In such realities, “there may well be, either in each sensory experience or in each consciousness, ‘phantoms’ which no rational approach can account for” (Merleau-Ponty, 1962, p. 220).

May was released from hospital “on the wrong dose of drugs (…) about three times the right dosage.”

It just made the whole experience a whole lot more traumatic than it needed to be. I was fainting. Each time I would faint, I was on the toilet, so I would faint with my pants down. The first time I didn’t know because I was sitting on the toilet and for some reason, as I fainted, I got up from the toilet and tried to run. Run out of the bathroom. I just remember that sick feeling. (…) It was disgusting. Like I was going to the toilet, like I was throwing up, my eyes were burning, my head was burning. I sat down, then plopped over. I started fitting that time and I had to wait till I stopped fitting before they could pick me up. (…) It meant that it was serious, that something was definitely wrong.

Surrealists attempt to capture such a hermeneutic account of body-emotionality (Gordon, 1999). Such dialogue brings body-experience that usually remains hidden, into the visibility of image. The image of the text is also the raw honesty that authors, filmmakers, poets and artists strive to achieve in an authentic work. Hence, the
emotionality of body acts, such as fainting, being exposed, attempting to escape, being sick and in seizure, renders anxiety and fear accessible to others.

When asked about fear, May replied, “fibrillation is my fear.” May spoke of ventricular tachycardia as her heart racing while fibrillation was when the heart “just goes to jelly.” May elaborated on tachycardia.

Its like a fluttering, like a butterfly fluttering. My heartbeat is so strong. I can feel it all the time. I can feel it sitting here with my legs crossed. When I go to bed at night my whole body beats, and I can feel it in my neck and in my chest. So when you can’t feel that, it becomes just like a flutter. Like you can’t feel a pulse. (...) I was really scared. What would happen next? Well, I knew it just couldn’t keep up that rate. It was uncontrollable. So I thought if we don’t get that under control, what happens next? Do I faint? Do I die? Do I …[silence]? I was sweating at the time. Sweating profusely. My breathing was erratic and very shallow. (...) Fibrillation is my fear. (...) I have to die sometime but I would rather it was not now.

The etymology of “butterfly” is the ancient Greek symbol of consciousness, soul, breath and life (Rabuzzi, 1997). The arrhythmic heart compared to a fluttering butterfly conjures the image of a fluttering consciousness or soul in the throes of escaping from the body. Much like the common reality of a butterfly fluttering in vain to escape entanglement from a web. Moreover, the synonymous meanings for “fluttering” fit with May’s emotionality and body-feelings: “make one’s blood run cold; one’s flesh creep; take away one’s breath; pale as death; haunted with the fear of” (Dictionary.com., 2002). Hugh’s emotionality was similar in his dialogue on tachycardia, “Ah, … [difficulty] its like … ah, how can you say it. It is like a butterfly in your chest. (...) Very emotional.” Jock also felt “a bit of a flutter, so I just sit down.” There was no sense that implantation provided any relief from the fear of fibrillation, because fibrillation, at the very least, meant bioelectronic shock and failing that fibrillation meant the ultimate liminality, death. Thus, it was apparent that emotionality featured as a significant component in relation to heart implantation regardless of gender.

IMPLANTATION AS BODY-SEXUALITY/GENDER

In this study, three females and six males became aware of heart implantation permeating their body-sexuality and their gender, albeit in various and complex ways. Body-existence and sexuality/gender are co-extensive because the projects and desires
that bring actualization to human beings are fused with self-identity. In other words, “there is interfusion between sexuality and existence, so that it is impossible to determine, in a given decision or action, the proportion of sexual to other motivations” (Merleau-Ponty, 1962, p. 169). For males in this study, choice of profession was imperative to self-identity. At the top of his profession Jock expressed disappointment and stress post-implantation.

The part I am a little bit disappointed in his having to retire earlier than I intended to do. (...) I had all those goals. But having to retire early and having to refinance things and see how we could survive, that was fairly stressful to me. We are living with that now.

The responsibility for achieving goals begins and ends with the body (Frank, 1995). Jock’s intention was to fulfil his self-actualisation by choosing the appropriate time to leave his profession. Post-implantation his self-identity as a successful male became “stressful” as he struggled with less than the life he had been capable of providing pre-implantation. Hugh expressed the “loss” of having been “a physically orientated person all my life.”

Not being able to do all those sorts of things builds up in your mind. You feel so useless. (...) The whole world comes crashing down and you can’t work again … to productively earn a living … to be what you are.

Hugh’s inner dialogue was steeped in hopelessness. Pre-implantation his body-self and gender-identity had represented his being-in-the-world. Post-implantation Hugh’s “whole world” crashed, robbing him of peace of mind; usefulness; and productivity. Hugh perceived implantation as having robbed him of being who he was; this stolen identity was reinforced by Hugh’s disembodied second person ‘you’ rather than an embodied first person ‘I.’

A contrast in sexuality/gender experience affected Simon’s pre-implantation situation.

I was worried about … there’s lots of times people put on things [pretend] to get out of things [work]. They get called malingerers and I just wanted to get back to work. Not get bailed out as a big sook. I didn’t want to cause all this trouble of getting ambulances … I was guilty. I felt guilty. It was just underneath my mind the whole time you know (...). It doesn’t hurt as much as you reckon it does and you’re just putting on this thing to get this attention (...) until they started telling me they were going to electrocute me. I guess that was sort of Yahoo Serious.
Simon felt that his cultural male sexuality/gender was under scrutiny when he collapsed amidst his colleagues in a male dominated profession. This situation was unacceptable to Simon because it was contrary to his belief in his male identity. His concern was that he would be labelled a “malingerer,” “a big sook,” and “trouble.” These labels, common in his profession, caused Simon guilt. There was a crisis of meaning in relation to the strong, healthy body that Simon now rejected. The body as the “ultimate arbiter of truth” responded to Simon’s situation with nausea, dizziness and pain (Butler & Rosenblum, 1991, p. 136). A “Yahoo Serious” situation existed for Simon in relation to defibrillation as electrocution of his male body. Electrocution as an extreme of human behaviour, portrayed in the film Young Einstein (Pead, 1988), captured Simon’s imagination. Yahoo Serious is a pseudonym adopted by a young Australian actor in this film. As a literary device, yahoo serious is compact conflict or an oxymoron (Pearsall & Hanks, 2001). This device allowed the actor to portray culturally and historically important issues within a comically surreal paradigm.

Similar to other male recipients in this study, Simon’s situation post-implantation separated him from his profession.

I was still assuming it [ICD] would not have any effect on my employment or anything. So in that regard I just thought … whatever, just stick it in, it wouldn’t make that much difference. But probably if I had realized it [ICD] would mean that I’d lose my job … I probably would not have gotten it in, you know?

They perceived that their arrhythmic heart was insufficient cause to lose their chosen professions. The reality was, heart implantation with an ICD “would mean that I’d lose my job.” Jay confirmed, after being in his profession for many years with cardiac dysfunction, the situation changed post-implantation with the ICD; “there was quite a bit of anxiety;” “there was little contact;” “I found that stressful;” “I felt that there was very little support;” “the feeling was, what will we do with you;” “you would be more of a liability.” In this way the ICD became a symbol of pejorative labelling and stigma. The cultural perception of masculinity defies the concepts of dependence and reliance. The etymology of stigma is from the Greek, “to mark or brand” (Kleinman, 1988, p. 158). Implantation as sexuality/gender for male recipients in this study produced “the signs [that] were cut into the body and advertised that the bearer was a blemished person, ritually polluted, to be avoided, especially in public places” (Goffman, 1963, p. 108).
1). Herein lies the fear that fosters a lack of understanding, both of the human condition and of bioelectronics. Heart implantation with a bioelectronic device also caused sexuality/gender insecurity in private. As a gender contrast, there was no loss of profession for females in this study.

**Interfusion between sexuality/gender and existence**

Together with the words in the above title (Merleau-Ponty, 1962, p. 168), Jay’s hermeneutical account confirmed the existential cost to his sexuality and gender perception post-implantation.

I suppose, something very personal, it [ICD] has an affect on sexual activity, which is something … for a man is something that is probably very hard to come to … to adjust to. I have just recently discussed it with my GP [general practitioner]. He said there is a new drug coming out.

There are many technologies of sexuality and gender (de Lauretis, 1987). Jay touched on several of these technologies when he spoke of “something very personal;” the ICD; “sexual activity;” “a man;” adjusting; discussing it; medical intervention; “a new drug.” Implantation of the heart with an ICD was able to reach into every aspect of living, no matter how intimate. Consequently, the intimacies of human interaction could never have the same existential meaning enjoyed pre-implantation. Jay expanded on his situation.

Through trial and error, some things I’ve had to back away from physically … Activities and so on … sexual activity because that has caused pain.

Throughout the cultures of the world a male’s self/gender identity has been interfused with “sexual activity” (Westheimer & Lopater, 2002). Jay and other males in this study felt strongly that it was not “OK” to be given extended life through the ICD when implantation cost their sexual performance and their gender identity.

It is not just, OK, we have implanted the thing, away you go for the rest of your life. It just does not work that way. I don’t feel happy about it. There is the fear that the device could discharge during [sexual] activity.

To be angry, unhappy and fearful about a specific situation is an expression of a moral stance (Harre, 1991). Jay’s statement alerts the reader to the morality of protecting the interfusion between sexuality and existence from intrusive bioelectronics. “Culturally dominated moralities have long been associated with health and emotions; the
appropriateness of how to grieve, how to love; and involve bringing them together in ‘dying of a broken heart’” (James & Gabe, 1996, p. 9). Jay grieved the “decline” of his “central,” sexual role.

There has been a decline in [sexual] activity, and that, as a man … that has been fairly significant, fairly central to a man. A more powerful, I feel anyhow, a more powerful urge within a man than within a woman. From an emotional and physical point of view, I can only speak for myself. Probably a man is more the initiator of activity. Yes, it is something very central and very personal.

This type of grief seethes with the emotionality of ambiguity. While recipients of implantation were enabled to live, the “powerful urge” of sexual activity that is interfused with a man’s existence was often suppressed by fear of ICD shock. The price of implantation in relation to sexuality/gender was deprivation of something significant, emotional, physical, very central, very personal and the role of initiator.

Simon, Noel and Jock also endured this deprivation. Simon “was concerned when it [implantation] first happened and we probably waited a fair while before doing anything [intimate].” As a young, newly married man Noel experienced sexual deprivation post-implantation, “it was a bit of a shock. Like we could not be physical for a while.” Deprivation of physical intimacy “was um, difficult. Loss of independence and I felt I had lost it. That is a part I would never feel the same way about again. I had trouble dealing with it.” After a brief experiment with sex therapy Jock noted that his “sexual drive is not there as it was” pre-implantation. Thus, “sexuality is dramatic because we commit our whole personal life to it” (Merleau-Ponty, 1962, p. 171). Different forces shaped female recipients’ experience of sexuality/gender.

Female sexuality/gender invaded and violated

As I prepare for this section I reflect on my experience as a young, first-time mother with severe, acute mastitis. Medical students surrounded my hospital bed. Under the direction of the Professor of Surgery, they stared, and in turn palpated my engorged, inflamed and painful breast. Under this invasive scrutiny I mentally counted the squares on the hospital blanket to suppress the urge to curl into a fetal position. Dell’s hermeneutic account of invasiveness was sobering in its similarity.
As a growing girl, I had so many young student doctors coming in to listen to my chest. I had to have my shirt off and you know, I was like 14-15 [years of age]. Everyone would come through and listen to me like I was a guinea pig. They used me as a test. Can you spot what is wrong with this girl? I just felt like a piece of meat and that was very invasive. It still hurts now when I look back, because I think it warped me a little bit.

The trauma to and disembodiment of Dell’s sexuality/gender “has the impression that the alien gaze which runs over [her] body is stealing it from [her]” (Merleau-Ponty, 1962, p. 166). It could be said that Dell was objectified in this scenario and indeed that is true. But this fails to do justice to her trauma. In Merleau-Ponty’s chapter on sexual being he speaks of body significance as the central phenomenon. The image of a teenage girl with exposed breasts being used as an experimental object with no more subjectivity/femininity than a “piece of meat,” is an image of invasion and violation. Merleau-Ponty (1962, p. 167) in relation to the alien gaze, on one page alone, used the descriptors, “defenceless; servitude; shame and immodesty; self-defeating; master and slave; deprived of [her] freedom; autonomy and dependence; embarrassments and fears.” Thus, female sexuality/gender in the body’s sexual being is “what we try to possess, then, is not just a body, but a body brought to life by consciousness” (p. 167).

Dell’s experience of perceiving herself as a “guinea pig” extended to the possibility of future motherhood. “One of the big issues for me if I ever get pregnant, the biggest deterrent for me is, I don’t want to be a guinea pig, which I know I will be. I’ll have hundreds of doctors coming up to listen to me, and listen to the fetus and stuff like that. I don’t want that.” In effect, Dell was saying that she did not want her future baby’s heart viewed, examined, listened to, or the fetal environment displayed as a technological pregnancy on fetal ultrasonography (Sandelowski, 1994b). Dell reflected on sexual activity post-implantation.

There should be counsellors come and explain what it is going to be like when I have sex. So, if I’d had someone to talk to, it would have made things so much easier for me. Is it [ICD] going to go off, while we are having sex? And suddenly things were fun and exciting … a big difference for me. I didn’t tell him about my ICD for quite some time. I was very scared of telling him that I had an ICD. Who wants a damaged person for a relationship? But he was excellent about it. We got married a year later.

Throughout the cultures of the world there is idealization of the female body (Wendell, 1996). As a consequence, Dell felt alienated by the absence of support and information.
in relation to her body, which she perceived as not the ideal. Dell rejected her sexuality/gender as “damaged” post-implantation. Dell was fearful of body-rejection in a potential relationship because her sexuality/gender had been invaded by a “machinery of power that explores it, breaks it down and rearranges it” (Bartky, 1990, p. 80). In spite of the trauma and self-doubt Dell found acceptance.

Disputes with uninformed general practitioners had sexuality/gender overtones. “In part of the consultation I will say, I have an ICD. And they say, you mean an IUCD [intrauterine contraceptive device]. Treat me like I am a complete idiot. There is always a sexual connotation because I am young.” May’s experience of her sexuality/gender was similar yet different.

I had the [chest] x-ray at work. (…) and the males made jokes out of it. The truckies said if they had a flat battery at some stage they would use me as a jump lead [nervous laugh]. One of the fellows at work calls me bionic boobs [nervous laugh]. That was a bit strange. And of course that was what they looked at when they saw the x rays. Everyone of them, every male that looked at it said, “oh, I can see your boobs.” [nervous laugh]. That shocking, graphical, gross metal and wire, machinery, in there [chest] and they are looking at boobs!

While May sought support and acceptance from colleagues, because there were locations she was not able to enter with an implanted ICD, she was subjected to ridicule and violation of her sexuality/gender. “Bionic boobs” is an example of violating language that places femininity and sexuality/gender within an oppressive paradigm. In cruel and ignorant disregard of May’s implantation predicament a male pack-instinct to defile her femininity, “and use me as a jump lead,” may be seen as analogous to verbal violation of womanhood (Wendell, 1996). May’s plight did not improve.

Ah, I have flights of stairs I have to run up and down all day and I have to hold on to it [ICD], and they [males] all laugh, they get a chuck out of it.

In contrast to Dell, May has never been able to trust her femininity and sexuality/gender in a relationship commitment. “I used to date … what a drama. I am a bit scared. It is a pretty confronting thing for someone else to have to deal with it [ICD]. They could obviously feel it, yeah. No, it is an obstacle for me.” Although May wanted children she viewed the possibility as, “it’s not going to happen. Every relationship I’ve had I don’t let it get too serious.” May reflected on ending her sexual relationships, “oh, I always do. I just get scared. This is my own pathetic psychoanalysis, but while I think I might have a fantastic opportunity, I get more scared or I break it off.” Similar to
Dell, May perceived that implantation disembodied her sexuality/gender as “damaged.” Yet here the similarity ends, because May’s disembodiment included the insurmountable “obstacle” of body-paranoia, which taps the “intuitive connection between internal threats to the body and external threats” (Frank, 1995, p. 176).

Similar to Dell and May, yet not as traumatic, Jade felt she was not as feminine as women are culturally expected to be.

   Like I am going to be in a bridal party, so I can’t wear a low cut dress. Yeah, I have three boobs. It [ICD] is almost the same size. I bought my first push up bra when I got it [ICD] in. Yeah, everybody at work refers to me as (...) and the three boobs.

Jade portrayed her implanted, feminine body in a seemingly light-hearted manner. Yet she was acutely aware that her invaded and violated sexuality/gender could be captured in wedding photographs. Being called “three boobs” brings to mind the female genetic mutant cast in the popular science fiction movie, Total Recall (Feitshans & Shusett, 1990). The tag line of the film is that the principal character has his mind stolen but now he wants it back. However, in the science reality of heart implantation there is no ‘going back.’ Female sexuality/gender invasion with an ICD is permanent. In the science reality of heart implantation with an ICD, others played a significant role in their relationality with recipients.

IMPLANTATION AS BODY-RELATIONALITY

All nine recipients in this study were influenced by other people in their lives, in relation to their hearts and bodies being implanted with an ICD. Merleau-Ponty (1962, p. 353) explains that the things people do are constantly co-extensive of their relationality with other-selves.

   We have learned in individual perception not to conceive our perspective views as independent of each other; we know that they slip into each other and are brought together finally in the thing. In the same way we must learn to find the communication between one consciousness and another in one and the same world. In reality, the other is not shut up inside my perspective of the world, because this perspective itself has no definite limits, because it slips spontaneously into the other’s and because both are brought together in the one single world in which we all participate.
In this study, four recipients suffered sudden cardiac death episodes; two recipients required defibrillation during electrophysiological studies (EPS); two recipients were subjected to frequent, life-threatening ventricular tachycardia; and one recipient chose an ICD rather than a replacement pacemaker because of a high-risk familial background of sudden cardiac death.

Jock suffered sudden cardiac death in a public place where his spouse and an ambulance officer carried out cardio-pulmonary resuscitation (CPR). Jock had external defibrillation and was unconscious for five days. Having an existing cardiac history Jock deferred to “live with” the cardiologist’s recommendation that “I get fitted with an ICD. So I have had to live with it.” Hugh’s scenario was similar to Jock’s, yet dissimilar in that Hugh suffered three separate sudden cardiac death episodes at home. Hugh’s spouse accepted the cardiologist’s recommendation of heart implantation. Hugh was angered; “when I found out about it was when I was back in CCU [coronary care unit] with it [ICD] implanted in me.”

Yeah. I was angry. I took my anger out on my loved ones. Maybe I was angry at life, I don’t know. This is the point you know. When I got mine [ICD], nobody said, “this is how you are going to feel. This is what is going to happen.” It was all new.

Hugh was alienated from his body in the denial of his sense of self by others who held the power of life and death. In anger Hugh put forth his argument. “Nobody” acknowledged his living person. “Nobody” gave him the chance to know his epistemic emotionality. “Nobody” considered he had a subjective voice in relation to implantation of his heart and body. Thus, body-relationality became inessential to others in what “was all new.” More confidence was placed in the cardiologist’s metaphysical stance (Leder, 1990) than in communicating with Hugh. After years of anger and psychotherapy Hugh’s resignation was similar to Jock; “I would like to be living without it, but I have no choice. I have accepted it that way.”

Dell and Stan shared a similar experience in many ways where they felt that others had control over their hearts and bodies. Both suffered sudden cardiac death episodes, Dell in public and Stan in private. Both were resuscitated, defibrillated, unconscious for a period of time, and ventilated in ICU. Both suffered memory loss, confusion and disorientation. Dell’s parents accepted the cardiologist’s recommendation because,
“obviously I really didn’t have a clue what was going on. So, it was an enormous shock, so suddenly, at the gym working out and then having an ICD whacked into me.” Dell’s relationality with everybody was altered in complex ways post-implantation. Support from family exacerbated survivor guilt because Dell perceived, “I just felt like I had dragged everybody down so far. I didn’t want to drag them down any further.” Patient education booklets on ICDs were provided, but proved ineffective in content, context and relationality.

Dell perceived that body-relationality was out of reach, “I just felt like … trying to get any information and everyone just kept kicking me back. It was terrible.” The striving after information and understanding of our own humanness alters body-relationality and “we are encouraged to view ourselves as mechanisms and thus as fundamental enigmas” (Zaner, 1983, p. 154). As a perceived enigma Dell felt “I was a different person. I am still a different person.” Cardiologists that Dell approached did not understand her dilemma. “They all sort of said, “but you have an ICD. Your whole life is fantastic now. You don’t have to worry about it anymore.” There was no understanding.” After much family pleading and distress, Dell was referred to a psychologist who “helped me clear up a lot of things.” This was the beneficent relationality for which Dell had been searching.

Unlike Dell, Stan experienced electrophysiology studies (EPS), which he found “weird.” No information was offered by the cardiologist, that Stan could remember, therefore he had no understanding of the purpose of EPS; “Like they were making it [heart] go at a faster heart rate to see if they could make it do it again [arrest].” Body-relationality was in the form of a “pre-eminently visual object groomed in the ways of quite specific, all-pervasive,” diagnostic image on a television screen (Sheets-Johnstone, 1992, p. 3). Despite EP studies to establish a cause for Stan’s sudden cardiac death episode, “It [heart] stayed the way it is.” Stan pursued body-relationality with four separate cardiologists for opinions concerning his implanted heart, which had no definitive diagnosis, only to be told; “you are stuffed.” Similar to Hugh, Stan was angered. The cardiologist wrote that, “I had a choice of ICD or drugs. And I don’t
remember getting a choice. He just said, “you’re going to have one of these [ICD] in.””

During Stan’s attempts at communication with others he was labelled pejoratively as the “angry little bloke in the corner.”

The cardiologists they’re arrogant bastards. So they just don’t tell you anything. As I said, it was like, bang, bang, bang, bang. And then out the door. See you later.

Noel also felt dismissed by the cardiologist; “you go away and deal with the diagnosis I have just given you.”

All recipients in this study were unanimous about their body-relationality in the post-implantation check-up. “That’s when you want more care. For your first check-up they just, its like going in the electric chair. They just shove you in the chair, buckle you all up and the thing goes whim!” (Stan). What recipients were seeking after sudden cardiac death, and its traumatic aftermath, was epistemic validation (Wendell, 1996). Just as phantom limb was invalidated as “purely psychic hallucinations conjured up by bereavement, mourning, or yearning” (Sacks, 1992, p. 45), and the epidemic of encephalomyelitis amongst staff at a London hospital was invalidated as mass hysteria (Ramsay, 1986), the trauma of sudden cardiac death may be invalidated by the life-extending ICD. In this study, implantation as body-relationality has missed out on epistemic validation.

**Body-invalidation by health professionals**

Jay’s attempts to communicate with cardiologists and cardiac nurses, stands as an exemplar for the other recipients. After a shock from the ICD Jay contacted a cardiologist; “well, virtually he said that the defibrillator was working. So, what are you concerned about? So carry on regardless.” A second contact remained focused on the ICD.

I was not really happy about that. (…) But he said much the same thing. But if I was concerned at all, he would have a look at the device. So that was my first encounter with, what do you do, after the device fires, and what sort of response do you get? As far as (…) was concerned the device was working. What are you worried about? I wasn’t too impressed at the time. I felt that (…) could be more empathetic to your concerns. The cardiologist was a little bit dismissive, and probably left a bit to be desired.
It is apparent here that biotechnology is not neutral (Heidegger, 1977). The firing of the device constituted the power of biotechnology to evoke contrasting perspectives. When the recipients’ subjectivity was traumatized by the ICD shock, the support of reassurance and understanding was the minimum of expectation. However, the cardiologist dismissed subjectivity in favour of biotechnology objectivity. These contrasting perspectives are poles apart and thus cannot coincide. In Merleau-Ponty’s (1962, p. 361) words, “I may well believe that he is an inhabitant of another world in which my own thoughts and actions are unworthy of a place.” Jay elaborated.

Recipient’s invalidation of anxiety and concern left them in a solitary reality where they were “the only one.” The myth of the “great success” of biotechnology as totally beneficent to humanness is viewed as a consequence of the attitude of those who are technologically preoccupied (Greenberg & Schachterle, 1992). Cardiac nurses were included in this situation.

When I spoke to this RN [registered nurse] at (…) she seemed less than helpful. She did not give me much of a hearing at all. So I just let the whole thing drop. (…) The RNs have been very non-committal and dismissive. I feel I would get more empathy if I had a broken leg [sardonic laugh].

Jay’s encounter with cardiologists and cardiac nurses echoed the other recipient’s viewpoint.

I think they are technicians. I think they are professionals. They distance themselves from the patient. I believe you are just a case study. You might be interesting, but you are only interesting while you are in hospital and you have something that they need to decide on how to treat it. (…) We do the best we can and if he dies, well, we did the best we could. We offered everything we could, got him to sign a consent form and if it didn’t work out, something happened in the operating theatre, well, you hear stories about that. They are professionals and perhaps they build it into their career to distance themselves from … so they don’t become emotionally involved.

Abandoned by body-invalidation, recipients felt their subjectivity was reduced to “just a case study,” and to “a consent form.” Merleau-Ponty (1962, p. 359) elaborated on such a situation where people distance themselves from subjective others. “I escape from every involvement and transcend others in so far as every situation and every other
person must be experienced by me in order to exist in my eyes.” Moreover, from a
Heideggerian view, it appears that biotechnology has the power to push its human
innovators beyond the limits of their humanness (Greenberg & Schachterle, 1992).
However unintentional by health professionals, recipients in this study perceived
implantation of their heart and body as invalidated body-relationality. Noel’s
summation captured the situation in phenomenological language. “It would help the
medical profession to understand what it is actually, physically like to go through. They
don’t get tested on it. They would have incredibly more understanding. I think that is
important.” Conversely, family member’s influence was validating.

**Being validated by family members**

There can be no doubt that family dynamics and relationality influenced recipients in
this study to endure and persist with the anguish that accompanied heart and body
implantation with an ICD. Dell elaborated on this situation.

> Oh, you will die, you will die, if we take it [ICD] out. I couldn’t care less. But
> then (…) would be in tears and (…) would be in tears and then it is your duty to
> keep it in. The duty thing, duty has always been a big deal to me. But that was
> the biggest duty. I just wanted it [ICD] gone. I didn’t want it and I didn’t care if
> I died, could not have cared less. Be glad. I was praying to be dead. I prayed,
> please, I don’t want to wake up in the morning, or help me get hit by a car
tomorrow or whatever. I did not want to be alive. But then you can hardly turn
around and say that to your parents, you know?

For Dell death was body-relief, death was freedom of spirit; the art of dying had
prepared Dell for a good demise (Lee, 1996) that the ICD rendered ambiguous. Yet
there was the higher consciousness of family, those multiple selves that
Merleau-Ponty (1962, p. 359) made explicit; “Solitude and communication cannot be
the two horns of a dilemma, but two ‘moments’ of one phenomenon, since in fact other
people do exist for me.” Dell felt duty bound to continue living for family others who
existed for her and validated her anguish. Similar to Dell, Jade was influenced by duty
to family.
It is part of today. You still think about getting out of life and taking the easy way out, but I don’t think it is easy. Hated it [ICD]. Hated eating. Hated cooking. Hated going to sleep. Hated getting up. But I have to (nervous laugh). [Smoking] It was defiance … I know it can kill you so I don’t care. Nobody could have stopped me had I wanted to. And I am still like that now. (Refuse ICD?) I think because (…) the bond was stronger [with spouse]. I don’t think I could have done it to my Mum (nervous laugh). Probably Mum, I could not have done it.

Jay’s experience was similar yet different in that Jay actively resisted implantation. At least 12 months … it would have taken me to resign myself. It was pointed out to me by one of the cardiologists. Although he probably wasn’t putting pressure on me in a direct sense, indirectly it was a bit of a jolt to say, “well, we just can’t keep this up.” I suppose that is medical advice and you can only be guided by the opinion of the experts. So-called experts. I decided to agree to the implant consultation with my wife, of course. She was very much involved in the drama attached. On each occasion she had driven me over to the hospital. She would take me over at 2 o’clock in the morning and things like that, so she was sort of saying, “you need something done.” So I guess I was getting advice there too (nervous laugh). It was a definite fear of the unknown. What was this thing going to do? What … I don’t like the idea of having something implanted there and giving electric shock. I think it was that fear of the electric shock.

During illness the body has a voice (Frank, 1995), the body speaks eloquently and exquisitely through the racing heartbeat, the loss of breath, dizziness and pain. But Jay was not listening to his body and was sceptical of “conflicting cardiologists.” Jay’s attention remained elusive until the voice of his spouse emphasized the voice of his body. “That was a big motivation to … hey, I’ve still got a wife, I’ve still got a spouse who wants me to be here” (nervous laugh). Noel was also fearful of the “unknown” and like Jay he wanted to share his life with his spouse.

I find it hard where I am expected to trust my whole life to one aspect of not being anxious. I get confused as to why I get so anxious. There is … apprehension. Fear of the unknown. I have a fear of how long I will be around with my wife. I have a fear of will I pass this condition on to my child. I don’t want it to spoil my life.

Being validated by his new spouse pre-implantation brought unexpected fears into Noel’s relationality. Having lost both parents at a young age possibly exacerbated Noel’s “fear of the unknown” with regard to family relationality. He felt “incredibly blessed” to have family validation; “she supported me.” Similarly, Simon found support and validation in the presence of his spouse while in CCU; “she came in and I
saw her … settled me down a little bit as well because there were strangers all around
me.” Being at home with their new infant encouraged Simon; “I’m actually looking
forward. That’s probably the first time I am looking forward to getting interested in
something.” In being validated by family, “already the other body has ceased to be a
mere fragment of the world, and become the theatre of a certain process of elaboration,
a certain ‘view’ of the world” (Merleau-Ponty, 1962, p. 353).

**Validation of the ICD**

During recipients’ dialogue there was occasional reference to heart implantation with
the ICD as a life-saving, life extending phenomenon. These positives have already been
included in excerpts. However, a specific hermeneutical question was required to
determine what validation existed for the ICD. For example, Jade’s answer to the
question: What do you believe about the ICD? “Here I am, I have got this thing [ICD].
Well, it has saved my life once. Its um, well basically it is there to stop me dying. Like
the one time that it has gone off I was asleep. Had I not had it in there I would be dead
now basically.” Hugh had never experienced a shock from the ICD. This caused his
answer to be rather tenuous. “I think it was a gradual thing that you have to realize that
you are reliant on something mechanical, you know. And you think to yourself, is it
going to work? I think that is the thing that gets at you psychologically. Is it going to
work if that happens to you?” Simon’s answer was more positive but still ambivalent.
“I don’t know. Backup I guess, sort of. Yeah, it is your safety net, I guess. If all falls
to bits, that’s your backup plan. If it is not going to help you then not much else is, sort
of thing.” Jock’s answer indicated that he felt responsible for the activation of the ICD.
“I am trying to control it. I am trying to look after myself knowing it [ICD] is there as a
backup. If something goes wrong, if I did something silly or too stressful, it might go
off. If it does go off I’ll have to fix it.” Dell’s answer was non-committal. “A box, a
metal box. It [ICD] is there. It does its job, end of story. If I don’t bother it, it doesn’t
bother me. That kind of relationship.”

The concepts represented by recipients’ beliefs in relation to the ICD varied
considerably. Recipients answered the hermeneutical question according to the effects
of the ICD on their body and their lived-world. In Merleau-Ponty’s words: “Before
becoming the indication of a concept it is first of all an event which grips my body, and
this grip circumscribes the area of significance to which it has reference” (1962, p. 235). The body-relationality recipients experienced in the grip of heart implantation with a permanent ICD yielded a degree of validation from their individual frame of reference.

The area of significance to which family members of recipients have a frame of reference in this study is explored in the following chapter.
CHAPTER FIVE

INTERPRETING THEMATIC PERSPECTIVES IN
FAMILY MEMBERS’ DIALOGUE

INTRODUCTION

Family members are the second group of key players who participated in this study of heart implantation with a permanent ICD. The existential knowledge to be found in the dialogue of family members is multidimensional and thus contributes invaluable depth to the overall understanding of the study phenomenon. Family members’ experiential knowing emanates from being those who are closest to the recipients of ICDs, and from being those who are linked to the liminal ramifications of potential death, altered living, and heart implantation. By being close to recipients, family members experience connectedness to the phenomenon of heart implantation, albeit from a different perspective. In this way family members are the peripheral players who not only fill in some of the experiential gaps unfilled by recipients, but also become engulfed in a personal state of body-liminality, such as grief, through their connection to heart implantation. These family members are spouses, mothers, fathers, and a sibling. Table Two presents the thematic framework from family members’ frame of reference, and sub-themes are outlined according to the perspectives arising from family members’ dialogue. Pertinent verbatim excerpts are provided to exemplify themes.
### Thematic Concepts: Table Two

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### IMPLANTATION AS BEING LINKED TO BODY-LIMINALITY

I draw the reader’s attention again to the photograph at the beginning of this thesis. The Liminal Body is there for the reader to connect with. The reader may marvel at what medical biotechnology can implant within the heart and body in order to extend life; the reader may grow pale with the shock of visual invasiveness; the reader may recoil in horror from the cyborg connection; or the reader may simply turn away. Whatever the response to The Liminal Body the reader can never experience the essence of body-liminality in relation to heart implantation with an ICD. How much more complex and traumatic for family members for whom the reality of The Liminal Body was that of a spouse, a child, or a sibling? Family members initially became involved in heart implantation through resuscitation attempts during the liminal state of sudden cardiac death. This allowed family members a window of opportunity to reach across the threshold between life and death in the retrieval bid that “finds its way to the core of my personal life and becomes inextricably linked with it” (Merleau-Ponty, 1962, p. 347). Thereafter, family members remain linked by their own body-liminality to the phenomenon of heart and body implantation with an ICD. Moreover, whatever the
circumstance of heart implantation, family members would live with the constancy of potential sudden death of their loved one.

**Being linked on the threshold of sudden cardiac death, pre-implantation: Spouses’ perspective**

The phenomenon of heart implantation began for most family members in this study with the trauma of witnessing the potential cardiac death of a loved one. This in itself portrays a liminal state in which family members’ lives would never again be the same. Witnessing the collapse of a spouse in the family home has been described as “an environment for conflict” (Sque, 2001, p. 106). Yet, this description appears inadequate in the context of this study. Writers dealing with sudden death in the home, focus mainly on interventions for family needs (Costain-Schou & Hewison, 1999). It was frustrating not to find literature that gave insight into the lived-world of the spouse in the throes of frantic resuscitation. Kara related her profoundly poignant attempts to retrieve her spouse who suffered a sudden cardiac death episode at home.

> We were sitting around after dinner talking about what happened at the carnival and he [spouse] just slumped from the waist over, made strange noises and (young son) screamed. Then I threw him on the floor and started CPR for about 10 minutes.

What began as an idyllic family interaction after an afternoon carnival, suddenly ended in a life and death struggle. Kara’s introduction to the phenomenon of heart implantation was “devastation,” which took her to the threshold of the potential death of her spouse. Kara continued in more depth.

> I just looked at him (...). I slapped him across the face and (choked with emotion) … Initially I thought he’d had a stroke. Then I just threw him on the floor and commenced cardiac and CPR. I guess while you are doing it, you don’t think about it. But after he was vomiting and it was revolting and fairly traumatic. I remember my knees were all scraped and my mouth was out here like this (indicated swollen). I must have been fairly aggressive for the mouth to be all banged up and on my knees, because it is a wooden deck. Pulling him off the chair and his head hit the chair. Then back on the floor. It wasn’t a genteel thing. It was a pretty rushed thing.

The pre-implantation experience for Kara, as for Zoe, was one of dissonance and the potential liminal state of widowhood; “What I think about is not how he would die, why, or if he would suffer, but just that he would not be around anymore” (Zoe).
Kara’s instincts told her that her spouse was entering the ultimate liminality, which is death (van Gennep, 1960), where he would be lost to her and their young family. This liminal situation was incongruous with what Kara was prepared to accept. In desperation Kara aggressively fought to prevent “a stroke” or sudden cardiac death from taking her spouse over the threshold into death, which excluded her. Kara’s vividly described body-liminality linkage brings to mind lines six and seven from the poem by Dylan Thomas titled, And Death Shall Have No Dominion; “Though they go (…) Though they sink (…) And death shall have no dominion” (Thomas, 1969, p. 245). Even though resuscitation attempts were “revolting” and “traumatic,” Kara refused to allow death to have dominion. Her encounter with what was to be heart implantation with an ICD began with her being “all banged up.”

In pre-implantation experience, Bev’s linkage to body-liminality differed, yet was similar. Bev similarly felt “devastated” as she observed her spouse living a life that “was not as he wanted it to be.”

He would just sit down and he would be asleep within five minutes. He would have to stop half way up the stairs and sit down. If we went out anywhere, we could not be any longer than one hour because he could not stay awake, and he was always out of breath. That was no way to live life. Um, it was very hard. It was happening to somebody who had been active before, and then all of a sudden to go down like a sack of potatoes.

In a pre-implantation situation, Bev could only observe her spouse in liminal sleep, a life-threatening sleep where all others were excluded. In this way her spouse was gradually slipping away. Conversely, Bev described the crisis as “sudden.” Her metaphor “like a sack of potatoes,” related to inertness and the unceremonious state of a person (Pearsall & Hanks, 2001). Pre-implantation “devastation” affected Bev in a way that “was not helping my health. My blood pressure went sky high.” Bev was living her own body-liminality as “a living hell!” Subsequently, Bev’s spouse suffered a sudden cardiac death episode while travelling.

When he had the cardiac arrest he started turning blue, and purple, and every other colour (nervous laugh). And then, I saw all the blood run from the gash in his head. (…) I was just thankful there was an off duty ambulance man. (…) The ambulance man, he said, “lady, we have been to about 200 of these and your husband is the third one to survive.” So the odds are not good. You realise that it is a fine line, you know.
Bev’s linkage on the threshold of sudden cardiac death was different in three major circumstances. First, there were no young children present to compound the traumatic effects. Second, her spouse’s episode occurred in a public place rather than within the family home where memories surface on a daily basis. Third, Bev was fortunate to have a health professional nearby to render assistance. However, being witness to physical trauma and sudden death involving spouses was a commonality in a liminal state of their own; “I thought he had gone.” Bev captured the meaning of the threshold state between life and death; “it is a fine line.” Kara and Bev’s attempts to retrieve their spouses from the ultimate liminality of death describe vigorous CPR. It was a frantic action to maintain the physical body-connections that allow life to be lived through the body. In this way, “I find in the body, message-wires sent by the internal organs to the brain, which are installed by nature to provide the soul with the opportunity of feeling its body” (Merleau-Ponty, 1962, p. 76). In other words, vigorous CPR was the only way of forestalling the crossing of “a fine line” between life and death and endowed their spouse with the opportunity to hold on to Being. Parents would also struggle, within a liminal space, to maintain the “message-wires” of the physical body with Being, in relation to their child’s liminal state.

**Being linked to body-liminality, pre-implantation: Parents’ perspective**

The death of a child has been viewed as the most traumatic and the worst event a mother could endure (Rosof, 1994). As a mother, Jill’s pre-implantation experience on the threshold of life and death held double jeopardy; she temporarily lost living touch with her loved one and with her child. This would remain as part of the meaning of heart implantation with an ICD.

> My middle size [2nd child] daughter was calling me. I went into the bathroom and [1st child] was vomiting. She was unconscious. I dragged her out of the bathroom. What was it? Was it a stinger in the surf? Was it a toxin? What could account for this collapse? In about 10 seconds I was outside screaming for somebody else to ring an ambulance.

Once again, an idyllic family situation switched to mayhem in an instant. Such an instant, where a child who had been carefree and happy surfing, then snatched into sudden cardiac death, defies usual expression. Jill’s spontaneous expletive was; “This was the oh fuck!” situation that strikes dissonance, discord and indescribable distress.
into the being of a mother. Each was separate from the other by a liminal state; the mother losing a child; and the dying child. Jill elaborated.

I took over. Kneeling over her. Watching her. I got a great sense as a nurse, when a patient dies. You just know. I actually got hold of her and shook her vigorously. She actually reverted. Self reverted out of VF into VT. They carried [her] outside while they were charging the defib, to get her clear of everything. I was just a mother then. I was holding the [baby] screaming in my arms, had the [2nd child] looking absolutely terrified. She told me later on that she thought [1st child] was dead. At that stage I guess technically she was. I couldn’t go outside to watch the defibbing because I felt that was just something I couldn’t do.

The desperation in Jill’s dialogue is almost palpable. Her dual identity as mother and nurse combined as she watched over her child and her patient. Jill fought vigorously to hold onto her child who was leaving her to enter into cardiac death where neither the nurse nor the mother could cross the threshold. Jill could only scream, “DON’T DO THIS” and hope that somehow, somewhere across the threshold, her child would hear and respond. With the possibility of losing one child, Jill clung desperately to her other children. The threatening presence of death was terrifying in its unpredictability.

Mothers have described the sudden death of a child as deeply altering their sense of self as a mother; part of their self as a person dies with the child; and a profound sense of sadness becomes part of their embodiment (Gudmundsdottir, 2000). This situation was to become part of heart implantation with an ICD. Having nursing backgrounds, Kara, Bev and Jill agreed, “when you are working in the hospital and you have a terminally ill patient, you know in the end they are going to die, you can accept that, you know. But not when it is somebody very close to you, you can’t!” Body-liminality existed for both mother and child. The special bond between mother and child is different yet similar to the bond between father and child.

Overcome with emotion, Scott related his traumatic encounter with his child in ICU. This encounter would remain with Scott to form part of the essence of heart implantation.

In ICU I had to hold her down. They did not have enough nurses to hold her. She still had the [urinary] catheter. I had to because she said she wanted to get out of the bed all the time. I kept saying, “you have a catheter, you just go to the toilet where you are.” She could not understand. I will never forget that. She just did not understand. Her mind was not with it. She was in a terrible state.
The primal urge of needing to relieve bodily functions is an all too familiar scenario in ICU for health professionals. However, for a loving father trying to protect his child from further harm by physical restraint was, for Scott, an unforgettable trauma. Clark Moustakas (1996, p. 4) wrote an account of restraining his five-year-old daughter following open-heart surgery. As a father, Moustakas felt “the most intolerable realisation that she was beyond my reach, beyond my voice and touch. She was in pitiful plight; entirely by herself.” Such is the nature of heart implantation, where there is no crossing the threshold by family members; there exists a liminal state for both father and child. As a younger sibling, Beth’s link to body-liminality presented a different perspective to spouses and parents.

**Being linked to body-liminality, pre-implantation: A sibling’s perspective**

Sibling relationships are ever changing and complex whether the bond be one of harmony or conflict (Ashton & Ashton, 2000). Furthermore, siblings have a bond that is not always shared with other members of their family. When one sibling has a life-threatening illness, the impact on a sibling, especially a sibling of the same gender, can be so deeply imbedded as to remain hidden until a sudden death episode eventuates (Faux, 1991). Beth was a youngster when her older sibling suffered the first of two sudden cardiac death episodes; “that affected me quite deeply (…) it was really hard for me to accept that [she] couldn’t come and play with me when I was a kid. (…) It is hard for children to understand I think.” This was Beth’s linkage to heart implantation and body-liminality. It was also her own liminal state; “I was often terribly afraid that she would die and leave me.”

Beth witnessed her sibling’s second cardiac death episode as a young adult and found that “from a very early age there was a lot of pressure to cope,” was more than she could bear.
She just dropped down, just totally. She was holding a bottle of water and she just fell to the side and I remember seeing this water spraying everywhere. She just hit the ground with a loud, WHACK on the head. We started doing the whole rescue thing and I was trying to clear out her mouth but she had clamped her teeth in a seizure thing. It must have been some sort of muscle spasm with the heart going into VT. I knew, because her colour went strange. I started to really get upset and one of the gym ladies said, “shouldn’t you be starting CPR now?” So I rolled her over onto her back. She was still making this gasping sound like her teeth clamped. I think I was just sitting there holding on to her foot or something while they were working on her. I couldn’t think. The paramedics came and you know it is bad when the paramedic comes in and goes, “holy shit!” I knew it was bad anyway. They had to cut her T-shirt and cut her bra and start doing things with the paddles. I had to keep holding on to her. I don’t know why. I could not let go of her. I felt somehow I was keeping her there by keeping contact.

Not even a life-time of living with her sibling’s illness could prepare the young, adult Beth for the responsibility of attempting to reclaim her older sibling from the liminality of pre-implantation death. Being witness to the throes of a sibling’s death struggle involving the discoloured body, the contortions of seizure, and the “gasping” sounds of escaping life, rendered Beth powerless and paralysed. This sense of total paralysis within reality engenders an inability to act, to think, to do the things that are normally spontaneous; it is a liminal wasteland; “I was totally overloaded.” Beth was trained in CPR yet when faced with her sibling’s potential sudden death, the self became childlike, helpless and out of control (Lewis, 1992). In such situations the self can experience the sensations of physical freezing, leadenness and numbness (Wurmser, 1995). Beth’s pre-implantation experience of reaching across the threshold of sudden cardiac death became a physical “holding on” and “keeping her there by keeping contact.” It was unthinkable “to let her go” because Beth believed from early childhood, “that was my job, my responsibility.” The time of Beth’s “worst fear” had eventuated, yet no amount of preparation could sustain her in a liminal hour of need. Time could never erase what heart implantation would mean for Beth during reflection; “You know, you just think, this is it, this horror we have been living with has finally emerged.” Family members realised their crises through the unique language of body-liminality. The symptomatology of the body (Frank, 1995) that lingers betwixt and between life and death, speaks a language already described in the preceding pages. Thus, family members would be confronted with heart implantation on a different level in the body-relationality of the medical encounter, altered family living, and the impact of the ICD.
IMPLANTATION AS BODY-RELATIONALITY

Confrontation on a new level entailed experiencing a loved one in the physical-world of the medical encounter. Health professionals assessing the language of the body such as, symptoms of sudden cardiac death envisage the body as object; Zoe elaborated. “He [spouse] is just a heart; a heart condition to them [cardiologists], with a defibrillator. I don’t know what you can do to change that.” Merleau-Ponty (1962, p. 73) described this situation as; “The definition of the object is that consequently it acknowledges between its parts, or between itself and other objects only external and mechanical relationships.” Jill related how health professionals claimed ownership of heart implantation when her young daughter survived a sudden cardiac death episode; “I am angry, a lot of ongoing anger about other people thinking they have the right to have some ownership to what goes on within a family.”

They said, “oh, we’ll be fitting a defibrillator next week.” No way! A registrar came up to me to sign the consent form and I said, “well, I’ve got a few questions. I am not prepared to sign that until I have some answers.” Um, so that was a case where I thought that others made assumptions about how a family operates and about health consumers. There was clearly a made decision, to put a defibrillator in, and then they asked us. And that got my back up a lot because we have got some choices here haven’t we?

In this study family members were not happy with the degree of ownership in heart implantation decision-making allowed them by cardiologists; “It would have been good for him [spouse] being offered options (…) the knowledge now, you could have done this and this before we got to the implant [ICD]” (Deb). As in other studies family members were critical of lack of information and absence of potentially alternative treatments before being expected to sign consent forms (Sainio, Laurie & Eriksson, 2001). Australian cardiologist, Tony Donald wrote in his foreword in The Insulted Heart (Hersey, 1996); “I am sure I am as guilty as many other cardiologists, due to time constraints, of not counselling patients clearly.” However, Jill and her spouse “just wanted to be as informed as possible prior to the decision;” and Zoe felt angry because “so far everyone I have had contact with, with [spouse], has not given me a warm fuzzy feeling kind of thing.” Ownership of heart implantation for their child brought judgement upon Jill and her spouse.
He [cardiologist] said, “I believe you are having some doubts about putting in
the defibrillator.” (…) I guess he sat there trying to give us a hard sell. We
came away from that discussion feeling like he was telling us that we are a
failure as parents because we are not going for the safest option. He concurred
with me about the feelings that he was very unhappy about us trying to even
make the decision. I mean, how dare we as parents want to make a choice in
this decision? So that had an impact on us, just put our backs up and we
thought, no, we are in this decision and we have a right to discharge her [child]
if we want, we have a right to a defib, if we do or don’t want.

Heart implantation evokes two conflicting concepts of uncertainty; for family members
there is the existential uncertainty of making a choice that loved ones may accept; for
the cardiologist there is clinical uncertainty where a predicted outcome is missing
(Adamson, 1997). With differing perspectives it is fair to say that existential
uncertainties that affect the life-world of a child or spouse, inevitably intersect with and
are shaped by clinical uncertainties. Conversely, Scott was unable to establish any
meaningful relationship with a physician who, “as far as he was concerned, she
[daughter] should just get on with her life and she should accept it [ICD] as being the
most wonderful thing that has ever happened to her and; what was wrong?” Scott
elaborated.

She was not able to cope mentally because she was incapable of having the
mental processes to handle that; the whole idea of this thing [ICD]. And as
[spouse] said, as well as that, she was a young female, a young woman who was
very conscious of her body and that. So she was hit doubly with a mental
problem and then with a normal attitude that she would have had anyway with
having this thing put in her body, I feel. But of this, nobody spoke to us.
Nobody really spoke to us at that level of what we should expect, or what we
could do for her.

Technological metaphors used to describe the ‘self’ that physicians present when
consulting with patients and family members include, “self honed and calibrated, and a
dissociated virtual image” (Gothill & Armstrong, 1999, p. 8). Thus, the subjectivity of
Scott’s daughter was excluded from heart implantation. Similarly with Kara’s spouse;
“One [cardiologist] came in and said, as a second opinion, I don’t know what you’re
whinging about. You are going to get a good payout. Take it [ICD] and if that doesn’t
work, don’t go on anything for five years and see how you go.” Other family members
agreed; “The doctor he [spouse] struck was not very sympathetic to the cause” (Pam);
“That cardiologist, he was very arrogant, that was horrible. That was really horrible,
you know. There was no empathy. Just, you stop your whinging, and that was just
horrible” (Kara); “I think it is their [cardiologists’] manner anyway. They’ve got no social skills. They knew what they were talking about and they didn’t want any interference at all” (Deb). Consequently, uncertainty surrounding heart implantation was exacerbated for family members because body-relationality was not person-focused; the focus was the ICD. Post implantation confusion arose because family general practitioners were uninformed; “Our local doctor did not know anything about it at all. One thing he did say was, you mean he is never going to die?” (Bev). Kara’s summation spoke for all family members in this study.

I don’t think the person is considered at all. A lot of people have said, “there is just not enough support for the whole thing.” You know its all the technical stuff [ICD]. Its more technical stuff than anything else, we’ve got this thing here, let’s put it in and we’ll get rid of that problem. We are very clever we can do this. That’s not … that’s just the way it is.

Deb also confirmed that follow up focused on the ICD rather than the person.

Once the device is implanted they don’t care about the person, because the device is there to protect the person. You’re fine now you’ve got the device. I think you’re happy too. If it zaps too much then the battery gets used up. So we’d better give you medication to stop it zapping too much. So again they’re still concerned about the device. It’s not like, oh no, it’s zapping you too much, it’s hurting you.

Although cardiac nurses were not mentioned at length in this study, family members expected more support from nurses in heart implantation. Beth’s account compared health professionals.

They sent a student nurse in to take the blood and it took her like six times, and we were incredibly distressed. (…) I mean, some of the nurses were excellent but the doctors, a lot of them really grated on me. (…) I mean, we had just been through this huge thing and he started making these crass jokes about [sister] showing her wares around the hospital, because when she did not have anything on and when she tried to sit up the blanket fell down. It was totally tasteless you know. We were distressed as it was and he carried on like a fool and you couldn’t put your trust in someone like that. But another doctor was very good. He was very good and sensitive and tried to put himself on the patient’s level.

In contrast, as a nurse, June’s family encounter with cardiac nurses was disparaging; “We have just been disgusted with the cardiac nurses all round. We just feel that they have been appalling. They have done nothing at all to help any of us.” Scott expressed perceived abandonment.
It makes you lose faith in the medical profession. [Spouse] was a nurse and I expect, she is a good nurse, and I expect people to be treated the way she would treat a patient. And I did not really see that. There was a little bit but not what I would think would be good nursing practice. For such a complex issue, for such a … you know, going through death and coming back and having all that [daughter] had to go through and then just to have this technical thing [ICD] stuck in her chest … go home now. That is where it failed me. But what I could do about it was very little. It just made me feel inadequate more than anything.

Perceived abandonment projects a lack of caring or a lack of ‘being there’ in “good nursing practice.” Caring qualities attributed to nurses such as, commitment and advocacy (Montgomery, 1993) appear to be absent from this study of heart implantation. There is the opposite dimension to caring where “caring itself requires the ability to choose not to care, and to have the wisdom to know what to care about” (Montgomery, 1997, p. 79). Personal experience as a cardiac nurse persuades me that this statement from Carol Montgomery is one of the most insightful in relation to cardiology. This is discussed more in the following chapter. However, body-relationality between family members and health professionals was tested and family members experienced a loss of faith, trauma, being “failed,” and being “inadequate.” June added a description of abandonment.

Nobody would ever get over that. Seeing your child so distressed, there is nothing more you can do. You have done everything you can possibly do. And really seeing both your daughters so distressed, one for the other, they have always been very close, it was just impossible … impossible to bear. It was just so … you felt absolutely helpless. [We] could not make anybody hear. I was screaming out. “Could somebody come and help us here.” Nobody made any attempt to help. [Daughter] was yelling out. She was obviously terribly distressed. There should have been somebody there. Of course there should.

Heart implantation in this study meant that family members were alone in the human condition. The final verse of Human Condition, written by Thom Gunn (1969) captures human Being in the condition of unknowing as problems alter well-being; the condition of realising the elusiveness of understanding; the condition of questioning; and the condition of ultimate aloneness.

Much is unknowable.
No problem shall be faced
Until the problem is;
I, born to fog, to waste,
Walk through hypothesis,
An individual.
Being in relationality with the ICD

Family members in this study were closely linked to the decision of heart implantation with an ICD. Life preservation and life extension through biotechnology is seductive (Gasset, 1972). Family members’ initial relationality with ICD biotechnology emanated from their fear of not having their loved one in-the-world. However, because family members reported not being adequately informed or educated in relation to how their life-world would alter following heart implantation, their knowledge accumulated from secondary knowing. Merleau-Ponty (1962, p. 324) wrote of coming to know things-in-the-world.

For our human existence, the thing is much less a pole, which attracts than one which repels. We do not begin by knowing the perspective aspects of the thing; it is not mediated by our senses, our sensations or our perspectives; we go straight to it, and it is only in a secondary way that we become aware of the limits of our knowledge and of ourselves as knowing.

Deb spoke of how she came to know what her relationality with heart implantation and the ICD entailed.

Oh, first he [spouse] came home all confident you know; its not going to do anything. Then he got five shocks from the device within a few weeks. He went from being really confident and in denial; like its not going to affect him, into; he couldn’t do anything. Like you couldn’t do anything. Go up to him from behind and tap him on the shoulder; “Oh, don’t scare me.” We lived in a unit and he didn’t like going up the stairs. He’d go up a bit and rest and so he went from one extreme to the other.

This was part of secondary knowing and relationality of heart implantation and the ICD to which Merleau-Ponty’s excerpt can be related; losing confidence, being fearful, and being altered from “one extreme to the other.” Thus, Deb’s life-world changed because her spouse was not the person to whom she was accustomed. Deb explained other ways of knowing.
He had a little device. The heart monitor wasn’t very accurate but it helped him and he could see what his heart was like. But he relied on it too much and if you took it away from him, he just panicked. We were in a shopping centre and because of whatever was going through the place, it affected the device and he’d look at it and it would be beeping irrationally. He’d think it was him so we’d sit him down and calm him down. It got really annoying because, like little things that I took for granted. [Spouse] “Oh, I can’t do that or don’t scare me, or come up behind me and tap me on the shoulder.” Like, I knew I had to wait for him to get through that over sensitive stage. Even drinking, he wouldn’t drink coke, coffee, anything with caffeine in it for fear that it would increase his heart speed.

It is apparent from these excerpts that heart implantation and the ICD altered the life-world of all who were linked with a recipient of the ICD. No longer being able to take “little things for granted,” was “annoying” and heart implantation induced the label of being “over sensitive.” Constant uncertainty rendered relationality difficult. Family, friends and associates were influenced in their interactions with the recipient because of the impact of heart implantation with an ICD. Jill expanded on this impact.

You don’t make the decision for an ICD once; you make it several times. Especially when you are dealing with a [teenager]; she has a life-time of this. Not like she is 65 years of age and may see two units. It is not just one person’s problem either. For someone who has an ICD, it is the whole network’s problem. Everybody has some ownership of it. Although it belongs to the individual, there are other stakeholders as well. The mums and dads, the sisters, the carers, the health care workers, the GP who has to deal with this thing that they know very little about. The dentist … the school dentist freaked when I wrote it on the form. I got a phone call about it. I said, “well, I’m buggered if I know, here is the number, ring up and ask.” So it is not just one person’s issue, it is everybody who touches that person’s life in a way.

The paradox of being in relationality with ICD biotechnology is that in one instance the ICD adds life, while in many other instances the ICD-effect inevitably subtracts from the lived-world of “stakeholders.” Coming to know the ICD-effect is to know that a biotechnological innovation can never resolve a singular problem without creating universal problems (Ellul, 1972). Pam detailed a number of these universal problems for all family members in this study.
Oh, that’s right, one night it was a bit distressing because he [spouse] has just gotten out of the shower and the machine went off. The next thing I heard this bang and it [ICD] had thrown him back against the wall in the bathroom. That was about the time it was going off quite frequently. That was when we were starting to think; enough is enough! That was distressing to have to go in and dry him off and that sort of thing because the machine had fired. And I thought, God, if the door had been locked, what would I have done? I think that period when the machine was firing more frequently than it should, that was a distressing time, because I was getting to think; is it alright or is it going to go off when we are having tea? Is he going to have food in his mouth when the machine goes off? All these things run through your mind. Or are we going to be out somewhere? Sometimes even now, we are driving somewhere and I think to myself, I hope the machine doesn’t go off while we are driving because I don’t know what my reaction would be. Would I cope with the situation?

The unpredictability of being in relationality with heart implantation and the ICD-effect was daunting for all family members. Ellul (1972, p. 96) claimed that technology, such as the ICD, “is intangible and unattackable precisely because everything is subject and subordinate to it.” In her interaction with heart implantation Pam relinquished her initial belief of being free of anxiety and distress; “I was so pleased when they gave him the defibrillator.” Taking a shower, having a meal, going out, and driving a vehicle, became interactions of every day living that were fraught with the determinate authority of heart implantation with the ICD. Zoe confirmed; “I know it [ICD] definitely affects what we do even in terms of going out with friends. And I talk about if I felt disappointed or just for me not to build up any resentment.” In her quest for relationality and understanding of heart implantation Zoe wished “I could feel what [spouse] felt; if I could have it [ICD] for one day instead of [spouse].”

Despite the disembodying experiences of anxiety and stress Pam’s final analysis of relationality with the ICD was positive.

Well, if it [ICD] improves that person’s quality of life then it is great. If that machine can make the heart do what it is supposed to be doing so that they can go on and experience those things like enjoying life, seeing the sun rise and set, because that machine is making their heart work, well, go for it.
Zoe’s analysis was ambivalent.

Umm. Yeah. Well, the first word I think of is a lump. It [ICD] sticks out a bit and gets in the way. But I like to think it is a lifesaver. Even though it has fired off lots of times and not done what we thought it would do, or supposed to do, it did save [spouse’s] life actually. It is not a cure for the heart condition. And it is not comfortable. For [spouse] or me. It is pretty cumbersome. Pretty big. It is just one of those things, our life involves that now.

Jill’s conclusion was positive in relation to the ICD, yet fearful of the outcome.

It is beyond comprehension to have to face that amount of pain and agony again. We told [daughter] that when it [ICD] is due for replacement, the decision will be hers entirely, whether she replaces it or whether she has it just removed. It is only there as a back up, as a last resort. It is not managing the condition. How are we going to live with that? I will be terrified, but she has a right to her life and we take the view that the defib is in there to give her a life. It is not the centre of her life. It is just to make sure life has got best option. [At this point in time this teenager had chosen not to accept a replacement ICD].

What the heart meant culturally to family members played a significant role in their relationality to heart implantation with the ICD.

**Being in relationality with the implanted heart**

Feeling her spouse’s heart beat assisted Zoe to acquire a degree of relationality with heart implantation.

I remember feeling more when it [heart] kind of skipped a beat. Like when he [spouse] says it is not in rhythm. You hear a beat, then you hear nothing. Then you hear this extra strong, ‘blup.’ That freaks me out much more because I think his heart has stopped. Then it starts with this surge that is not normal. To feel that is … I mean that is what happens with him a lot. But I still think that always sounds dangerous to me. One day that will happen and that is the last time that will happen.

Zoes’s attempts to relate to the implanted heart stemmed from her spouse “wanting it [ICD] removed altogether. He thought it was not worth the pain, the stress and the anxiety. To me it was just black and white. He would have died almost certainly if he did not have it. There were more pros than cons. He said, oh, you don’t know what it feels like.” Again, this is liminal exclusion of family members who remain linked but cannot know what heart implantation feels like. While culturally the heart is embodied in romanticism such as, passion and courage, Zoe experienced ‘the tell-tale heart’ (Poe,
1993); “I think that is one of the hardest things because it is one of the most visible things. Sometimes if he is not well and we are watching telly, he goes breathless. I can’t cuddle up to him because he feels really crowded. Like he needs that space to breathe.” Thus, family members perceived exclusion as part of the essence of heart implantation. Kara experienced its essence as “faith shaking.”

It’s a faith shaking experience I must say. When this happened to him [spouse] it made it even more traumatic because it [heart] symbolises the whole person that he is. It’s the thing that supposedly brings out love and all those sorts of things and that’s how they condition you: all those songs and poems. That’s why people are so traumatised when they have something that goes wrong with their heart. Not only does it beat to keep you alive, it pours out all these other things people think and that’s why the trauma is so great, I think.

Belief in the cultural meaning of the heart saturates human existence. For instance, even though existence is brief, Merleau-Ponty (1962, p. 332) reassures that “temporality is not some half-hearted existence.” The cultural meaning of heart permeates the mediums of film, literature, television and music. In his book on the prosody of poetry, Alfred Corn (1998) draws on the reader’s belief about the meaning of heart by naming his work, The Poem’s Heartbeat. Even though the mechanics of poem construction is discussed, the poem as a living entity is included. In this way Alfred Corn explains the essence of a poem. Thus, it was Kara’s belief that by altering her spouse’s heart, by heart implantation, the person he had been was also altered. Pams’ relationality to the heart was tempered with ambivalence.

I was just going to say the heart is life-giving. Without our heart operating and working we are not going to be in existence. I often think about the heart and what a wonderful job it does. Quite often in poems it is of a romantic nature like, she gave her heart to him or vice versa. You never see a lovely poem that says, without my heart I would not be in existence, I would not live and I would not breathe. I think more of the practical thing of the heart rather than the romantic. You know, its lovely to think that somebody is ‘soft-hearted;’ I sometimes think that expression. I don’t think the heart is just an organ but we couldn’t exist if we didn’t have our human heart to make us what we are. You can’t live without your heart beating. So to me if your heart is not working then you cannot become anything. Without the heart beating the person cannot become someone to express their emotions, feelings, and let people get to know them and experience them; without the heart that you can touch and feel beating. Sometimes I might just put my hand on my pulse, to me the heart is fantastic. It is wonderful, the number of times it beats in a day.

Beth began to better comprehend her sister’s dilemma in relation to the implanted heart when the concept of “part human and part machine” was discussed at university.
Yeah. They were talking about the internet and the future. And they said, “people with pacemakers or a prosthetic leg and all that sort of thing; are they androids?” And that really made me think you know. To [sister] it made it more obvious, this physical defect that she has. It is like the point of her suffering. It [ICD] is something that she can see and touch. So it embodies her suffering. And that is when I really started to understand why she hated it so much.

Beth’s insight into what the implanted heart could mean to her sister is analogous with a metaphor from Marsilio Ficino, a fifteenth century philosopher/physician; “The body is the shadow of the soul [self]” (Hassed, 2000, p. 5).

As has already been shown in this study of heart implantation, a person’s heart and self is often perceived as inseparable. Consequently, the potential exists for intense “suffering” in relation to hybridisation of the heart and cybernetics. In contrast, the culture of film served to lighten the trauma with humour; “We often joke that [sister] is invincible. The only way she could be killed would be to be beheaded (laugh). Sort of like the Highlander.” In Beth’s dialogue, as in many other family members’ dialogue, it was not possible to isolate a person’s implanted heart from the ICD.

I mean, she constantly felt she wanted to have it [ICD] taken out and I really tried to say to her how much, even if it didn’t mean anything to her, it helped us as well. She was worried about hurting us, and I said, “well, it would hurt us if you took it out and died. We would feel that we had not done everything we could to stop you from dying.” I think that helped a fair bit. I think trying to, I don’t know, saying, “do you want me to get one put in as well and we will be exactly the same (laugh).” I mean I was only going on, I was not exactly serious but in some ways I wanted to because I would be able to help her more; something to help. Apart from that reason, sometimes you feel like an outsider often, because it is such a very personal thing. You don’t know how it would feel to have that in [your heart].

In the above excerpt a second family member expresses the alienation and ‘outsiderness’ that is the liminal state where family members were located in this study. Family members desperately struggled to know and experience their loved ones’ heart implantation crisis, only to discover the impossibility of relationality to another person’s liminal place. The very word ‘implantation’ indicates space to be occupied. Implantation as body-relationality for family members in this study remained an uncertain place, an unknowable place, and a place locked-in the liminality of outsider. Considering the unbreakable bond of spatial/temporal relationality, time would consolidate the “outsider” relationship created by heart implantation.
IMPLANTATION AS BODY-TEMPORALITY/TIME

From family members’ perspective temporality/time played an inescapable part in the phenomenon of heart implantation. The way time influences lived-world was captured by Laurie Spurling (1977, p. 40):

> My lived experience of time is intimately related to an objective time which takes shape on the horizon of all modalities of existential time, to which all my experience is linked in some way, and which makes hours, days, months, years, etc., arise as fixed points.

There is no event that does not have the element of time implicated in the lived-through experience that also happens within space. In other words, “things co-exist in space because they are present to the same perceiving subject and enveloped in one and the same temporal wave” (Merleau-Ponty, 1962, p. 275). Kara was enveloped in a temporal wave of sudden cardiac death.

> I tried to throw holy water all over him [spouse] and frightened the ambulance men to death while they were trying to defib him. That was just a reflex thing and the ambulance men screamed to me: “Don’t do that, you’ll electrocute him.” It’s just a, help God, I need help here!

All family members related how the beginning of heart implantation with an ICD was a turning point in their lived-world. Kara elaborated.

> He was unconscious and he had some cerebral oedema. So they didn’t think he would survive first up, and if he was to survive they thought he could have been brain damaged because he’d been without oxygen for so long.

With Kara’s spouse unconscious in temporality terms, Kara faced lived-time alone, with a provisional diagnosis that she could be alone permanently. The length of time her spouse had been “without oxygen” was crucial to the possibility of how much survival time was left. Being without life sustaining oxygen “for so long” encapsulated a future lifespan of uncertainty.

> What is going to happen here and here and here, in the long term future? And of course that went in a second. All our plans and hopes and dreams had gone. So it was, we had to restart all over again.

In the pre-implantation timeframe Kara’s life-world prospects dissipated “in a second.” The concept of ‘in a second’ is difficult to conceive in terms of losing “plans, hopes,
and dreams” that constitute what most partners move towards over a lengthy period of time together. Suddenly, instead of sharing the same aspirations, there is a different perspective, a different focus, and a different challenge (Secrest, 2000). Because Kara’s lived-world was now unknown and unpredictable she had no sense of time; “we went through to intensive care and I don’t remember. I have no idea of time.” Bev’s experience was similar; “I did not think at all. I did not have a lot of thought. I did not have time. It just happened so quickly.”

The unpredictability of time and sudden death was experienced by June and Scott as parents.

[June] Finally, he [doctor] told us it could cause sudden death. That was quite a long way down the track actually and so …
[Scott] That was the turning point I suppose, in our attitude towards her condition. Having the realisation to suddenly … like that she could die at any time. Up until then we had not been told (…). It would have been far better for us. But I know we were never told.

After years of knowing that all was not as it should be with their child’s health, June and Scott were “finally” informed as to the possibility of “sudden” death. Yet June still clung to the time metaphor of “quite a long way down the track.” The flashback of the significance of the prognosis caused June to stop in mid-sentence. Scott also had difficulty in relating to the “turning point” of time when he learned his child could “suddenly (…) die at any time.” The relationship between “then” and “never” was a timeframe when their lives would never be the same again. June reflected on her child’s antenatal time-near-death. “Her heart [rate] just disappeared. They couldn’t hear her fetal heart at all.” The unpredictability associated with life-threatening illness exacerbates the effects families deal with, particularly when the family perceives their limitations to be linked with the absence of knowing (Stein & Lee, 1996).

In contrast, Zoe’s time of knowing heart implantation was as a new spouse. Zoe was impressed with the futuristic technology; “to see the progress there and to think it will probably get even easier with the way technology is going. They told us things like the battery life was five years. It would be just an overnight stay.” In temporality terms, “an overnight stay” and the effects of heart implantation would change Zoe’s perspective in complex and enduring ways. Sometimes, was a concept that occurred frequently in Zoe’s dialogue:
Sometimes if he says, “I’m OK,” I have to believe that what he is saying is right because he would tell me the truth. Sometimes if he is in pain for a long time, I will say, “are you worried?” Sometimes he has been worried that he is not going to come out of it [survive]. Sometimes he is in pain and he gets breathless. Sometimes [he] has been woken up in his sleep and he has thought it [ICD] has fired off.

These are the times that Zoe could never have imagined being part of her lived-world as a new spouse. Whatever period of time would be allotted to Zoe and her spouse, there would never be a time when she did not live every day with the uncertainty of life-threatening illness and the permanency of the ICD. In the words of A.E. Housman (1969, p. 148); “The heart of man has long been sore and long ‘tis like to be.”

**Being on a wave of temporality**

When spouses are first called upon to deal with life-threatening situations, they enter into an unexpected and foreign world. While previously fit and well, the ill spouse may never have experienced incapacity or hospitalisation. This perplexing situation presents a temporal wave of fundamental life changes for family members. Being faced with the potential death of a spouse, life in the family home must still remain a priority, together with support of the spouse (Ellis-Hill, 2001). Pam had spent all day preparing “a dinner party. The table was all set up, the whole bit.” This was an everyday family leading everyday lives; “Then I got a phone call.” That was the night Pam’s spouse “had his heart attack.” Time was not on Pam’s side as she attended to all that needed to be done and undone in relation to locating her spouse, securing emergency treatment and hospitalisation, having two young children cared for, and cancelling the dinner party. Dealing with family matters became a time of mayhem.

Then I went up to the hospital and of course by the time I got there they had (spouse) with little plugs and things all over him. (…) he was in hospital for a month. Then he came home and that was a very trying time. In the end we had a big barny.

Pam’s dialogue and lived-experience was enveloped by a wave of time and events that threatened to swamp the family “in the end.” Such times of family disruption during the illness of a spouse is a time of temporary and or permanent separation for each family member (Reder, McClure & Jolley, 2000). Each family member is a unique
individual with individual needs that, prior to illness disruption, could be met within a satisfactory time frame. However, illness disruption includes a time when family members are separated in a liminal time warp of their own because of the break in unity.

Jill related to the concept of separation when her child was in CCU and her spouse was being recalled from compassionate leave of absence from his overseas commitment; “during that time she was on the monitor because every time we talked about separation, she would run a small track of VT.” Jill was linked to time and liminality through a period when her child’s medication was altered; “During that time it [ICD] has fired off twice (…), the first one put her into VF, the second one got her out of it.” In this experience, an instance of the potential negative time-effect of heart implantation with the ICD is revealed. Set within specific heart-rate time parameters, the ICD fired as a result of the pharmacokinetics of medication rather than actual ‘out-of-time’ arrhythmia. This firing resulted in VF which then required the ICD to fire legitimately. Although a temporary setback, the benefits of implantation and biotechnology are seductive because they lead us to overlook the potentially negative interactions of technologies (Teich, 2000).

Pam spoke of how time, biotechnology and heart implantation became part of her everyday life.

I convinced him that we should go to the hospital. They took one look at him and put the paddles on him. (…) It turned out it was his first episode of the cardiac, ah, the ventricular … the VT. This was our first experience of it. They had to slow the heartbeat down. He continued to have episodes of the problem, but it always seemed to be about two o’clock in the morning. (…) When they put the defibrillator in, that seemed to help me with coping.

Over a period of time Pam’s lived-world revolved around the constancy of her spouse’s cardiac problems. Pam was linked to body-liminality; “I feel that I am living with (spouse’s) condition everyday.” With the added responsibility of a chronically ill spouse Pam felt part of the VT episodes in referring to “our first experience of it.” Continually having to transport her spouse to hospital at two o’clock in the morning contributed to Pam’s acceptance of implantation and the ICD as a coping mechanism. Temporality/time is represented in Pam’s dialogue. For example, “first episode; first experience; slow the heartbeat down; always two o’clock in the morning.” Accepting biotechnology can be a state of mind as well as a state of culture (Postman, 2000).
other words, those who feel most benefited by heart implantation are those whose most profound dilemmas are compounded by the biotechnology.

Time and liminality were linked in Kara’s reflection on CPR. “It was a good ten minutes before the ambulance came. They say … how many ‘out of hospital’ cardiac arrests survive? And five minutes maximum time you can administer CPR anyway before they are brain damaged.” During this time of attempted retrieval Kara was alone. She believed her spouse was dead; “when your time is up, that’s it.” Yet Kara continued her efforts to remain linked. Being with a loved one near death and in death is like willing your own heartbeat and deep breathing to take over his/her life sustaining function, so that contact may be restored for even the briefest time (Moustakas, 1996). Kara voiced her thoughts on death; “It’s a necessary evil. No, I don’t think about it particularly. Like most people I suppose. If you are going to die, you are going to die. Not a whole lot you can do about it. I thought his time was up. Yet, I hoped.” The time of death is both temporal and spatial; “it arises from sensibility which has preceded it and which will outlive it, just as my birth and death belong to a natality and a mortality which are anonymous” (Merleau-Ponty, 1962, p. 216).

IMPLANTATION AS BODY-SPATIALITY/MOVEMENT

Implantation of a person’s heart with an ICD has the potential to disrupt the lived-world of people who move within the immediate space in proximity to a recipient. This potentiality is likely to constrain interaction with family members and friends. Body-spatiality/movement was discussed by Merleau-Ponty (1962, p. 283).

The perception of space (…) its modalities are always an expression of the total life of the subject, the energy with which he [she] tends towards a future through his body and his world. Once the experience of spatiality is related to our implantation in the world, there will always be a primary spatiality for each modality of this implantation.
Pam recounted her perspective when the ICD fired at her wedding anniversary and threw her spouse “onto the ground.”

From my point of view, if we went out anywhere I would think, gee, I hope (…) doesn’t have an episode because it would make me feel a bit embarrassed. Actually, (…) we had some friends and we went to a social. The machine fired and it was one of the strong episodes. It threw him back onto the ground, onto the floor. And when it happened, because it was a severe one, it was a bit painful apparently, and he sort of went white. All our guests that were there, they were open-mouthed because they had never seen this happen before. So he just had to sit for a while and it sort of broke the party up a bit.

From Pam’s perspective, venturing into public places always caused anticipatory apprehension because of the unpredictability of her spouse’s implanted “machine.” A wedding anniversary is a spatiotemporal occasion of celebration in the lives of spouses. The expectation of the occasion is one of pride, achievement and happiness. However, the visible manifestation of the invisible space of heart implantation would render Pam’s spouse severely shocked and white with pain. The gestured movement in space, from guests, was open mouth disbelief. How can being linked to the essence of heart implantation be captured in space and time? Lines from the poem, The Hour is Lost, epitomises poignant loss (Neilson, 1969, p. 147):

Our hearts burned hot within us ere we knew …
Then suddenly we said, Can it be true
This golden time was ours? – and now downcast
We stand dumb and amazed. Alas! The hour is past.

Being witness to the trauma of heart implantation with an ICD included being trapped in liminal spaces within personal Being and within liminal open spaces. Pam elaborated.

With this other situation [ICD] it was a lot of trial and error actually. In this situation every person is an individual and each has a different reaction; with how it is going to affect them. I found it a lot harder to come to terms with that. I suppose because of the pain of this machine firing. That was a higher level of anxiety to me because you witness this person being thrown back. We were out walking one day, and it went off at the higher level, and he was just thrown back on the ground. So you think, God, do I just leave him there for a while? - which we did, and then of course, we had to get home. We had a fair way to walk. I thought, should I go and get the car? Then I thought that if I left him he would be worse. So we just slowly went home. You are never without it, really! Although to have the machine is good, it is always there. The problem is always there.
Pam described her disembodiment in a situation of “trial and error.” Being linked in a spatial situation of heart implantation with an ICD divided sense of self because “each has a different reaction to the situation.” Pam could never experience her spouse’s pain, yet she was linked by the pain of her “anxiety” in witnessing his being “thrown” through space. From a vantage point of witnessing a situation she was afraid to enter, there was the opportunity to turn away. However, leaving her spouse was not an option because Pam was part of this spatial situation. Pam was trapped by ambivalence on many levels, but her final analysis was that while “the machine is good,” it is an inescapable “problem.” These problem situations of space and movement prompt the seeking of home anchorage; “it is from the heart (…) the distress felt (…) is caused by the fact that it brings home to us our contingency, the uncaused and tireless impulse which drives us to seek an anchorage and to surmount ourselves in things” (Merleau-Ponty, 1962, p. 283).

**Being unable to surmount liminal-space**

Being witness to traumatic events, whether viewed within open space or within closed space, has been found to either distort or heighten the detail of the event in the eyewitness account (Berkowitz, 2000). Furthermore, the confinement of eyewitnesses within the closed space of banks and stores during robberies tended to contribute to more detail, while open space trauma tended to focus attention on escape to a perceived safe space. Pam’s confinement in her own home was; “Oh, well, that was terrible.”

I would go into almost panic mode. Even though I knew the machine was doing it’s job, when it sort of threw him back. It [ICD] was doing it frequently. Like the machine was going off frequently. He was sitting there in the lounge, and it went off. Then half an hour later it did it again. So then he was almost frightened to move because he was thinking, Oh, God, if I move it might go off again and I might hit my head, you know. And we both then got into an anxiety state because it was happening so frequently. (…) even with the machine. It was not stabilising.

Pam’s eyewitness account of her linkage to being unable to surmount the threat of what heart implantation with “the machine” meant, is similar in detail to a hostage situation. Pam used the descriptors, “terrible; panic; threw him back; frightened to move; I might hit my head; anxiety state; not stabilising.” In this situation, body-spatiality/movement was under threat from the ICD that “was doing its job.” Pam’s conclusion about this
threat was that “it does make you think doesn’t it?” This reflection emanated from Pam’s dilemma about implantation. Implantation was life-extending, yet part of the spatial essence of implantation was “terrible, panic, and anxiety.”

Beth’s perspective on being linked to body-spatiality/movement was keenly different. Post-implantation, Beth viewed body-spatiality in her sibling in ways that mystified her and linked her to a liminal space, which was not accessible.

She was a completely different person. I didn’t know her at all when she came out of it. And when she was living with me again, it was just the strangest thing I have ever seen. It was like [she] was not there anymore. I still think it has changed her irrevocably. Like still, pieces of her are not the same as she was before the incident. I suppose that was the impression I had when she was lying on the floor unconscious, or dead I suppose, … is that she was not there. I don’t know. It was a dead body, there was nothing in there at that time.

Beth experienced her sibling as a replaced identity within the same body-space. It was mystifying how the sibling identity Beth knew could now be gone and seemingly lost to a liminal space. Her sibling had “come out” of one liminal space to enter another, where she “was not there anymore.” This life-space mystery imposed distance between the siblings because of the strangeness and the “irrevocable” loss. During her sibling’s SCD episode, Beth was aware of a similar separation. Her sibling appeared to be far away and “not there” in death-spatiality. Beth perceived that there was no Being-in-death. The “impression of bodily space” was described as; “Sometimes motion is no longer seen, and people seem to be transported magically from one place to another. The subject is alone and forlorn in empty space (…) all [she] can see clearly is the space between things, and this space is empty” (Merleau-Ponty, 1962, p. 282). Paradoxically, heart implantation would eventually occupy body-space, yet Beth, as a sibling, would remain alone and forlorn.

In contrast, Scott’s perspective as a father focused on a more specific aspect of body-spatiality/movement. Prior to his child’s SCD episode and subsequent heart implantation with an ICD he had been inspired by her musical talent. Part of his child, who had returned through body-space, remained in a liminal space that brought a special sadness to the family.
It is not a conscious thing. With her piano, she has forgotten, technically, how to play now. Now she has a lot of trouble with that part of her brain. I don’t think that has come back. She sat down at home and tried to play a few times but she found it so difficult. She has put it behind her. Her singing I think is to do with her own … what she feels within. Like [spouse] says, I don’t think she feels complete enough yet to sing. But that is a small price to pay considering we have her with us still.

Referring back to Merleau-Ponty’s “impression of bodily space,” movement in body-space can be left behind during transportation within liminal space. The intensity of alienation and sadness within liminal space leaves behind an emptiness that contributes to a person’s incomplete-Being. As a mother, June’s perspective was more emotive; “She won’t touch the music side of it at all which I find very distressing. I enjoyed it so much. Purely selfish I suppose, but I can see that she is not happy enough to try. I think that is such a waste because she had so much talent.”

Beth’s movement through space-in-the-world was haunted by nightmares. Merleau-Ponty (1962, p. 285) wrote of night-space dealing with threats, exile, being shut off, and pushed away; “In dreaming as in myth we learn where the phenomenon is to be found, by feeling that towards which our desire goes out, what our hearts dreads, on what our life depends.” Beth narrated a recurring nightmare of her sibling’s SCD episode.

We were walking across the park. We were heading towards the car park. It was dark and the streetlights were on and (sibling) had a similar episode. She would just fall down and this time, instead of having her eyes just sort of half open, her eyes were wide open and she just sort of lay there and her eyes were blue. Her eyes are actually brown. And as she was dying she was actually speaking silently to me saying, “do something.” And I couldn’t do anything. I didn’t have a phone. I didn’t have [anything]. There was nothing around and I did not know where to go for help. I was screaming out for somebody to help and some people walked past and they wouldn’t hear me. Or they would look at me like I was crazy and keep walking. I went into a panic. I knew she was dying and there was nothing I could do. And I would wake up sweating.

The actual reality of the lived-through event would be relived repeatedly and “the feelings that are stirred up during the nightmare are exactly the same as those I felt during the incident.” Thus, body-space and distance between the real and the surreal failed to separate Beth from her “worst nightmare;” losing her sibling. The spatial environment of the ICU was vivid to Beth as a “foreign; very strange; hostile environment.”
I think when I saw her plugged up to all the machines with 6 needles in this arm and 4 in that one, that made me feel very upset because I think at the time we were concerned that she would be in a coma for the rest of her life. You know, may have some sort of brain damage. I might have to get used to seeing her like that with her mouth half open and tape over her eyes, and that sort of thing. It did not look like her. It seemed so foreign. It was a very strange environment in a lot of ways. I could see all the coloured wires and the coloured needles and the vein colours contrasting against that. So it stood out as an almost hostile environment.

The geography of spatial environments serves to either connect or dislocate the maps of personal, internal landscapes carried by people as part of their history (Nast & Pile, 1998). Beth had never entered the environment of an ICU. This environment seemed not to belong to body-space, as she knew it, so the effect was one of anonymity and intrusion. The image of her sibling was disquieting and engendered a heightened awareness of spatial detail, such as the contrasting wires, needles and colours. The potential for this environment to claim her sibling long-term epitomised a “hostile environment.” In contrast, June was familiar with ICU as a nurse and experienced escape in the environment; “Well, it was rather nice because you can escape from being a mother and I could think straight as a nurse. I could not think straight as a mother because the whole thing was so big. I could escape into the nurse and leave the mother.” Jill offered a similar perspective within the space of the CCU; “The bit of me that was nurse was building, the mother side of me was just controlling the panic.”

Thus, implantation as body-spatiality/movement impacted in many complex and contrasting ways within family members’ world-space.

**IMPLANTATION AS BODY-EMOTIONALITY**

Body-emotionality is the lived through sequence of self-feelings. Self-feelings often embrace more than one specific emotion. Self-feelings involve self-referents in that the emotionality constitutes the person who feels the emotion (Denzin, 1984). For example, it is emotionality that draws the penitent to the confession box. The emotionality that defines the person may be guilt, anger, or grief. Whatever emotion locates a person in a state of emotionality is both part of self and situation. James Joyce (1976, p. 400) wrote of such a penitent; “He bowed his head upon his hands, bidding his heart to be meek and humble (...). His blood began to murmur in his veins, murmuring like a sinful city summoned from its sleep to hear its doom. He stood up in terror and walked blindly
into the box. The slide clicked back and his heart bounded in his breast.” Such is the power of body-emotionality that it cuts to the core of self. Beth’s dialogue drifted frequently to the emotionality of guilt-feelings in the context of her sibling’s SCD episode.

I always feel bad about it (...) but I wasn’t thinking that day. I said, “oh, come on, let’s race up the hill.” I’ve always felt guilty about it. I was OK for a little while but then I started to … I felt bad about that too. That I didn’t do, that I didn’t do enough. That I should have been more prepared. You know, growing up with it I should have been calmer. But I guess I really didn’t expect it to happen.

Beth’s negative thoughts and feelings reflect a disturbed self-concept resulting from action and inaction that she perceived as contributing to unintentional harm (Berkowitz, 2000). Beth’s youthful action of “feeling a bit excited that day. A bit hyped up from exercise. Endorphins going crazy,” was perceived negatively in the context of her sibling’s SCD. Thus, Beth’s emotionality was that of feeling “bad” and “guilty.” Paradoxically, her perceived inaction “that I didn’t do enough,” stirred the same guilt-feelings, albeit for a different reason. In this way, guilt and blame combined in “I should have” statements. Beth elaborated on feelings of “guilt, fault and blame.”

I still felt very guilty because I couldn’t admit for a long time that I couldn’t do the CPR. I just felt in so many ways that it was my fault. I could have done something more, you know. It was my fault, her memory loss, because we did not know if her memory loss was permanent at that stage or temporary. You know, you go through all those guilt feelings and it was my fault somehow. You want to blame someone and you blame yourself I suppose.

There is no universal way of expressing the depth of emotionality in the concepts of guilt and blame (Pattison, 2000). The multiplicity of self-feelings and contextual differences involved in guilt and blame is overwhelming and the affective consequences encompass the whole of Being (Lewis, 1992). As a family member, the meaning of heart implantation with an ICD would always link Beth’s emotionality to a state of body-liminality. Jade’s feeling of guilt offered a contrasting context.

Jade’s emotionality flowed between that of a recipient, a nurse and a family member. She had written in her journal about her small daughters lost to SCD. Heart implantation was not yet available to children. “I should have known she had heart failure. I am a nurse. I see it everyday. Yes! Guilt trip number one.” Pattison (2000) wrote that a sense of shame could be the hidden companion to guilt. Jade was unable to
express her emotionality in this context and instead offered her ‘hidden’ journal. While the penitent has the opportunity to express feelings of guilt, there is no such atonement for the emotionality of shame, which becomes internalised (Lewis, 1992). Jade perceived that there was no atonement, given her knowledge; “I should have known.” In Lewis’ (1971, p. 42) words, “Insofar as guilt is a more articulated experience than shame, and a more dignified one, it may actually absorb shame affect.” As a commonality, being a mother and a nurse was no shield against circumstance. Jill misinterpreted her child’s imminent SCD episode; “There was initial anger that she was vomiting all over the toilet. I actually said, ‘if you are going to vomit, at least get it in the toilet.’ I thought she actually had her eyes shut and wasn’t unconscious.” The assimilation of guilt to grief was integral to heart implantation.

**Being-in-the-world of grief and loss**

Heart implantation was a “roller-coaster-ride” for all family members in this study. The term ‘emotion,’ derived from the Latin, emovere, originally meant “to migrate or to transfer from one place to another. It was also used to refer to states of agitation or perturbation, both physical and psychological” (Averill, 1996, p. 206). Hence, for family members in this study, there existed a migratory link with the liminal-body. This linkage was the emotionality of grief. Jill explained her feelings of shock and grief during her child’s SCD episode.

> It is this big emptiness you get. (…) you know when they die. It was that feeling. That instinctive, intuitive feeling came, and it was just absolutely terrifying. I screamed, as well as shaking, DON’T DO THIS! DON’T DO THIS! For that time when I was screaming and shaking, it was very primal. And after that it was then, just fear. I just knew that this was big shit. It was just the mother, and I went, Oh! Fuck! It was just shock absolutely. This was beyond; 10 times bigger than anything that happens in my normal everyday life. Even when I think back over a similar overwhelming emotion when I had a phone call to say my father had died unexpectedly; that he was now dead. That um, the size of that was probably a fifth of what I felt at this stage with my own child. There is nothing like losing a child.

Jill’s dialogue was passionate with the emotionality of “emptiness, terror, fear, shock,” and grief. Physical responses to emotionality such as, feeling instinctively, screaming, and shaking, are “primal,” in that they are “the representation of a former perception; a highly specific emotional essence. (…) I reach back for the word as my hand reaches
towards the part of my body which is being pricked” (Merleau-Ponty, 1962, p. 180).

Having already experienced the “overwhelming emotion” of the sudden death of a young father, Jill’s own analysis was that “nothing” compared to “losing a child.” Jade added meaning to the anguished lament of grief, “Instead of enjoying her life, I was engrossed in her death.” In his poem, A Lament, Percy Shelley (1969, p. 361) wrote:

Out of the day and night
A joy has taken flight:
Fresh spring, and summer, and winter hoar,
Move my faint heart with grief, but with delight
No more – Oh, never more!

The emotionality of Kara’s grief was described as her “worst nightmare” and like being frightened while watching a “horror movie.”

It was just horror I suppose. I don’t know. It was just it was really fright, horror. I don’t know. [Comparison?] Nothing! Nothing! I don’t think there is anything more frightening than having someone that you love, dying right before your eyes really, because that is what was happening. He was dead really, and I don’t think there is anything more heart rending. Apart from losing a child (…). It was a horror movie. It was a nightmare. It was a horror movie. The worst nightmare. It was terrible.

Kara used the descriptor “heart-rending” to encompass the body-emotionality of feeling while her beloved spouse was dying before her eyes. A synonymous phrase for ‘rend’ is “to tear to pieces” (Pearsall & Hanks, 2001). In effect, Kara’s body-emotionality in incomparable grief was that her heart was being torn to pieces. Similar to Jill, the only other unthinkable horror was the death of a child. However, the concept of “nothing” was a feature of Kara’s grief. The loss of her spouse was perceived as being in a state of nothingness. Grief was similar to watching and being lost in the virtual vacuum of horror-movie genre. Kara continued with her grief response when the ambulance left with her spouse.

I just left him there. I didn’t want to go. I just wanted to stay here [home]. My sister was forcing me out of the house to go to the hospital and I didn’t want to face anyone. I just didn’t think I could do it. I just … remember them chasing me round the house. It was just how I felt. I just didn’t want to face it anymore. I didn’t want to know what was happening. I was frightened I suppose. Frightened that he was dead. I did say to my sister, “he is dead.” (…) I didn’t think I would be able to cope. I was just numb. Really … lots of tears. When they put us in that little room and … I couldn’t stay there. I just had to walk. And I walked, and walked, and walked, up and down the corridor. I think they thought I was crazy. Perhaps I was: just backwards and forwards.
Being linked to body-liminality through grief, Kara was unable to grasp a reality too elusive and unsustainable. When a loved-one has been an intrinsic part of physical, emotional, and social being-in-the-world, the perception of his/her not being there is incomprehensive in its implications. The suddenness of this emotional trauma for the survivor evokes body-responses and emotionality that is closely linked to those of post-traumatic stress disorder (Rando, 1997). It is not part of family members’ reality to have a loved one no longer present and living in their lives. However, heart implantation with an ICD was a constant reminder for family members that the sense of life as they had known it, pre-implantation, had been taken from them. Even with the retrieval of loved ones, family members continued in the process of anticipatory grief.

**Being-in-the-anxious-world of anticipatory grief**

How does anticipatory grief impose upon people’s lives? When a life-threatening illness hovers over a family, there is the ever-present anticipation that a loved one will be taken from the family (Rando, 1997). Specifically, a spouse may need to sense the presence of a partner through the senses of touch, hearing and sight. There may be a reaching out in the middle of the night for reassurance, to allay the gut-felt anxiety. Such was Pam’s experience.

I had to reassure myself by rolling him over or I’d say, “are you awake?” He would say, “I was asleep, what are you doing?” I’d say, “I’m sorry.” Then I would have to try and cover how I was feeling. You know how sometimes someone breathes very quietly and you can’t hear? It would go through my mind, now, how can I execute this and find out if he is still alive, without making him feel anxious about what I am doing? I would lay there for about five minutes thinking (...). And it was really distressing. That was an anxious time. I didn’t want to stress him that I was worried too much about him. I had to make up little excuses like, you’re taking up my side of the bed, just to make sure he was still there.

The concept of heart implantation with an ICD was not endowed with the capacity to console Pam and other family members who lived every day in anxious, anticipatory grief that “it [death experience] could happen again.” Sleepless nights, concealing emotionality, a disturbed state of mind, fear of the unknown, anxiety, distress, worry, and making “sure he was still there,” are some of the generic modes of both post-traumatic stress disorder and anticipatory grief (Raphael, 1981).
Kara’s anticipatory grief was similar yet different in context. During a follow up dialogue Kara recalled her tears and grief while watching the film entitled, The Way We Were. The title and content of the film triggered the poignant emotionality of her anticipatory grief. Zoe experienced a similar emotional trigger after her spouse suffered a VT storm. “I like to think I was really tough and stuff. Then I watched something on TV (television) that made me cry and then I just couldn’t stop crying. Friends of mine thought I was really crazy.” Kara related how the trauma of SCD was always “right in front of your face,” despite heart implantation with the ICD.

All those clichés like people saying, “these things happen for a good reason.” It is rot! It happens and it is how you deal with it as to how it turns out in the end. But it is always there. I probably should have gone and had counselling I think. I probably would have been better off had I done that … which I did not do [sadness]. But you know it is always there. There is always the fear that it will happen again. [It is] Grief. Definitely grief. Absolutely! Yes. I guess it is the whole mortality bit. And it is right in front of your face, really! So. Definitely grief.

The anticipatory grief in a loved one’s potential dying process encompasses numerous overwhelming body-emotions and “debilitating” consequences. This especially relates to the traumatised survivor who suffers the “violent instantaneous shattering of his/her assumptive world” (Doka, 1997, p. 36). Anticipatory grief is ongoing, ever-changing and multidimensional (Rando, 1996). There is not the scope in this study to accommodate the losses involved in physicality, emotionality, and relationality. Kara elaborated on how she coped with a recent re-implantation to replace her spouse’s ICD.

I think the anxiety is a post thing. Like my anxiety has um, yes, I get more anxious now than I did [before]. I worry more about things than I would have, now. I get very anxious, yes, about things. It is very debilitating sometimes. You know, like its … with the kids, if they are late, if they don’t ring. If I don’t know where they are. It can be debilitating sometimes. I get very stressed and almost like panic attacks to some extent. I get a panic attack and usually it is all wrong. Like usually it is a waste of time and energy, but I can’t help it. Umm. It is a horrible feeling of dread and horror. Horrible feeling. Its like I just want to run away and hide somewhere. I guess that was my reaction when [spouse] had his second ICD. I just wanted to lie on the bed and go to sleep and not need to think about it until it was all over and everything was OK.

There was no need to search further to add meaning to the above verbatim excerpt. The excerpt captures the essence of the misnomer, anticipatory grief. The concept of anticipation is apparent in “panic attack; horrible feeling of dread; and run away and hide somewhere.” Likewise, the concept of grief threads throughout the dialogue and
brings to real life the body-emotionality of what it is like, being-in-the-anxious-world of anticipatory grief. Heart implantation with an ICD influenced interpersonal anxiety in the existential Being of body-sexuality/gender. As a male, a spouse, and a father, Scot expressed heart implantation; “It was just totally destroying. Emotionally, ground zero for emotion, I suppose.”

**IMPLANTATION AS BODY-SEXUALITY/GENDER**

Chronic illness can induce high levels of stress and anxiety in relation to sexual intimacy and the perception of self-concept (Drench, 2003). In this study, sexual partners, while not always content with their situation, appeared to accommodate the impact of heart implantation with resilience. Nevertheless, intimacy between partners where one is healthy and one is chronically ill, affects couples in very different ways. Merleau-Ponty (1962, p. 157) linked this situation to the intentional arc:

> We discover both that sexual life is one more form of original intentionality, and also bring to view the vital origins of perception, motility and representation by basing all these processes on an intentional arc which gives way in the patient, and which, in the normal subject, endows experience with its degree of vitality and fruitfulness.

As the healthy spouse Pam discussed the unlikelihood of resorting either to sex therapy or to medication for her spouse. Pam’s analysis of their situation was that “you have to weigh up the pros and cons. *Do you want to stay alive, or do you want to have sex every night?”* Pam was able to view their sexual life from both perspectives.

> I sometimes felt resentful because … not that I was a sex kitten or something like that … wanting sex every night, so in a way I suppose that has been good. But at the same time, it is like the forbidden fruit, what you can’t have, then that is what you want. Of course, that is very demoralising for him, because over recent times he has been unable to get an erection. He gets really frustrated, so it got to the stage now, where we really don’t try too much. (…) I think it is more of a male thing too, you know. They like to be able to perform.

Pam’s metaphor drew on the biblical account of Adam and Eve who ate of the “forbidden fruit.” This metaphor served to elucidate the delicate topic of sexual desire that is denied. Their situation resulted in times of resentment, disappointment, loss and frustration. Pam also acknowledged the self-perception issues associated with gender; as a healthy woman she was endowed with vitality and as a male her spouse needed to be virile. However, Pam perceived that their relationship stood on more solid
foundations; “I don’t think if affects our relationship that much because we have always been able to talk with each other through the whole of our marriage. It wasn’t just sex, it was our marriage.” Still, sexual desire persists.

You resent it a little bit and you think … oh, I don’t know, why did this happen so early in our marriage. I suppose what I am thinking is that when it could happen you say, oh, no, not tonight Josephine, whereas now that it is not happening I feel a bit disappointed that it is not happening. The choice has been taken away from me I suppose. I could say yay, or nay, and this has happened. So I sort of resent that a bit.

Sexuality/gender issues have been noted as one area of focus that initiates disappointment, frustration and resentment between spouses (Drench, 2003). People enter into sexual relationships and marriage with certain expectations, beliefs and fantasies about their partners and spouses. Expectations such as, being happy and problem-free in the long-term, lead to loss of control and “why” questions (Payne & Ellis-Hill, 2001). Pam questioned in several different contexts; “Why did it have to happen to me?” and, “Sometimes I sort of say, you know, why did this have to happen to me?” In contrast, Kara had been angered by an information telephone call after feeling excluded from heart implantation support.

I don’t think you should have to seek it out yourself. I think it is their job and they just need to be a little bit more holistic in their care. We should be able to get information. I don’t think … like that nurse who rang and asked me how my sex life was. That’s part of it post heart attack, and things in your relationship. But that’s not the most important part, not really. I just felt that was … I was just stunned about that one.

As a recently married couple, Zoe and her spouse experienced intimacy difficulties in relation to the ICD, post-implantation.

Yeah, I guess the ICD … when [spouse] knows his heart rate is increasing, and it is definitely distracting that he is worried about whether it will go off. I get worried that it will. And it is all my fault (laugh). So yeah, that is definitely a factor. It is just that it is something that we are both a part of and you know that it wouldn’t happen if I was not there (laugh). Being afraid of not knowing what will happen or what you think might happen, to the point where it has an effect on you, either physically or the way you are feeling might change what you do, or how you do things, because you are anxious.

Zoe felt protective of her spouse during intimacy, and even a little guilty that she was the woman of his desire. The potential for the ICD to deliver shock therapy during sexual exertion was a source of distraction, worry, “my fault,” fear, “not knowing,”
adverse “effect,” and anxiety. Many people choose to remain in anxiety-filled, intimate relationships rather than being apart, and this is testimony to the value placed on intimacy within chronic illness (Meares, 2000). However, the permanency of heart implantation with an ICD would always influence the quality of intimacy shared by most partners in this study. Feeling protective was a commonality across family member’s dialogue.

**Being protective within body-sexuality/gender**

Family members who live with a loved one who has a life-threatening illness, tend to live life day to day (Attig, 2000). In addition, there is a sense of knowing the need to make meaning of the present because the present may be all that remains. Family was important to Zoe; “We would love to start a family now … sometimes I think we should not waste any time because we don’t know how long or short our time is.” In discussing family, both Zoe and her spouse were each considerate of the other.

Yeah. Definitely an issue. We um, we want to have them and we went to the genetic counselling service. (…) [Spouse] was a bit more ‘ify’ I think because he was thinking of things like, what if he died and then I was left to raise a child by myself without a father. But I was thinking, well, if you go [die], it would be nice to have a reminder of you. We talked about how it was interesting, the different perspectives we were coming from.

Gender differences in confronting threatening circumstances such as, Zoe’s child fathered by her spouse would have a “50%” risk factor, has been explained as depending on what people want most to control (Berkowitz, 2000). Zoe’s protective mode appears to stem from wanting to control the inner fear of potentially losing her spouse by having his child, while her spouse wants to control the practical or external hardship his death would create. “We realise our perspectives are different because I don’t understand what he goes through and he says he would not want anyone to go through what he has gone through.” Pam’s protective caring was a contrast in many different ways.

When he came home from the hospital I used to lay awake at night, and I would listen for his breathing. You know, I would think, is he alright, is he awake, is he sleeping or has something happened? And very discreetly, I’d give him a bit of a push, or say, “move over.” He would say, “ what's wrong?” Then I would relax.
Because of the nature of spousal caring and concern it was impossible for Pam to distance herself from the intensity of perceived responsibility. The hidden caring-work carried out “discreetly” was not always obvious to ill spouses due to the camouflage constructed by the carer (Taylor, 2002). Conversely, there were times of concern that required open communication and resolution.

When I would go to work, I would probably ring him about three times a night. I remember one night I was nearly beside myself. It was summer time and he had gone out hosing in the yard. I rang and there was no answer. I rang about five minutes later and there was still no answer, so you can imagine I was almost packing up to come home.

In the lived-world of the spousal carer, efforts to be vigilant are not always appreciated (Ellis-Hill, 2001). Pam experienced the conflict of perceived over-protectiveness.

Each day that goes past that the machine does not go off, it is like a bonus. He shifted a pot plant the other day, and he got a bit of chest pain. That puts me into an anxiety state and for about ten minutes I am saying, “are you alright, you sure you are alright?” (Laugh). He says, “oh, for God’s sake, I won’t tell you anymore if you are going to carry on.”

Spousal carers live their lives in a way not only caring for their partner, but also caring about their partner in a protective mode (Stroebe, 2001). This allows little time for the carer to maintain his/her own identity. Pam attempted to avoid being totally absorbed in protecting her spouse.

He has always been a good husband, a good father, and he loves his family. Just living with someone with any health condition like that, there is always a certain amount of instability I suppose. You know, could it happen? But I have tried to block that out of my mind. When I leave the house, I try to leave it behind. I think I owe it to myself not to be thinking how [spouse] is going all day because I probably would not survive.

Paradoxically, the protective care of a father for his daughter, post-implantation, resulted in a time of estrangement. Gaining access to a clinical psychologist; “It was a stand up fight (…) which was pretty horrible for all of us (…) and that was the turning point.” Scott tried to explain through his tears and devastation. “When we all got in there together, because [daughter] and I were very close and she was starting to turn on me. She used to say she was losing my love … (tears) … of course that was (unable to continue).” Post-implanatation Scott had a daughter who was a stranger to him. As a
male and a distraught father Scott felt he needed to speak out and secure psychological help for his family.

   Yeah, and we needed it. We needed it. We needed that help, and it was not recognised. And it should have been recognised. Somebody should have recognised it within the system and nothing has changed to this day. It is still happening. You know they have had this big cardiac rehab shuffle up all over Australia because I know it is happening.

Clark Moustakas (1996, p. 5) knew the anguish of rejection and accusation whilst attempting to ‘stay with’ his daughter, post cardiac surgery. During his quest to live through her semi-conscious nightmare all the way, to protect her, “She looked at me with utter contempt and hatred. She was beyond my call.” Thus, family member carers, regardless of gender, remain on the fringe of body-liminality. Relief from isolation, fear, anxiety, guilt and grief was sought by family members through an ambivalent faith in the hybridisation of the arrhythmic heart and the ICD. Scott offered a summation of the phenomenon of heart implantation.

   I think her [daughter] quality of life is really better now than what it was before she had the ICD. It is just the psychological problem. That is it. And I cannot stress enough to anybody who reads your study that the medical people must address this problem. They are just losing half the battle. That is all it is. Technically they are doing a wonderful job but the person is suffering just so badly, and families suffer so badly, because they are not addressing the patient as a total being.

The focus of the next chapter is the perspective of cardiac nurses and paramedical personnel and the ways in which their perspective guides health practices in relation to heart implantation with an ICD.
CHAPTER SIX

INTERPRETING THEMATIC PERSPECTIVES IN CARDIAC NURSES’ AND PARAMEDICAL PERSONNELS’ DIALOGUE

INTRODUCTION

Cardiac nurses and allied health professionals are the third group of key players who participated in this study of heart implantation with a permanent ICD. This group is different from recipients and family members. Recipients and family members became involved in heart implantation through uncontrollable life-circumstances. In contrast, these health professionals made an individual choice to engage in the area of cardiology and to include the associated knowledge of the study phenomenon in their life-world. In this way, the group unknowingly chose van Gennep’s (1960) three-stage rites of passage where liminal separation from mainstream place-in-the-world locates people in a liminal transition before incorporation into their chosen place-in-the-world [van Gennep’s emphasis]. While cardiac nurses chose cardiology as part of their professional life, the paramedical practitioners unintentionally became involved in cardiology.

Why would cardiac nurses choose this specific liminal state? Elizabeth Teather (1999, p. 1) suggests, “Our passages, intensely personal, thread their way through, impact upon and are influenced by the institutional fabric of social life.” Hence, cardiac nurse’s perspectives on the study phenomenon are vital sources to assist understanding in this study, because of intensely personal life-choices that impact upon recipients and family members in this study. Cardiac nurses contribute more significantly than paramedical personnel in this chapter because of their closeness to the study phenomenon. The title RN is used to introduce cardiac nurses. Thereafter, only Christian names are used. Table Three continues the format utilised in Table One and Table Two in the past two chapters, albeit in a different order.
Thematic Concepts: Table Three

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**IMPLANTATION AS BODY-SEXUALITY/GENDER**

Cardiac nurses in this study were all experienced in cardiology with some having worked in the area for most of their nursing careers. Each was asked how it eventuated that the heart was his/her chosen interest. Body-sexuality/gender emerged with little gender-related difference in the dialogue with participants in this group. With twenty-five percent being males, the gender of participants in this group cannot be denied a place in their existential Being-in-the-world. Whatever circumstances, personal attributes, and personal interests influenced participants to choose cardiology as their professional activity, body-sexuality/gender is significant. At this point I refer back to the discussion on sexuality/gender in Chapter three. Merleau-Ponty (1962) explained that sexuality includes the life-projects of individuals regardless of gender. Furthermore, the epistemological activity of the body-person to establish his/her place-in-the-world was elucidated by Merleau-Ponty (1962, p. 154).

Our constant aim is to elucidate the primary function whereby we bring into existence, for ourselves, or take a hold upon, space, the object or the instrument, and to describe the body as the place where this appropriation occurs. Now so long as we considered space or the things perceived, it was not easy to rediscover the relationship between the embodied subject and its world, because it is transformed by its own activity into the intercourse between the epistemological subject and the object.
Similarities and differences in embodied activity

RN Sue’s passage into cardiology stemmed from an “intensely personal” perspective. One day, when Sue was in primary school, her father went to work and “he just didn’t come home; maybe it’s a fascination from when my father died. He had a massive heart attack.” Sue admitted to being “very frightened of hearts, as a nurse. Always thinking the patient who had the MI [myocardial infarction] and went to the toilet was going to drop dead in the toilet.” It was the patronising remark of a “smarty pants doctor” that “was just enough to spark my interest or determination” to venture into cardiology. He said “he was going down to coronary care where all those blonde-would-be-doctors worked. With the fear that I had, I just really love it.” Sue had related two gender-connected life-events that consolidated her desire to dedicate her life-project to cardiology where knowledge of heart implantation with an ICD had meaning.

RN Rae’s perspective on her life-project was similar, yet different. “I have had a real life of cardiac nursing all those years. Then I suppose it became more personalised for me when I realised I had quite a high family history of heart disease.” Apart from the personal predisposition to cardiac-related problems Rae was amazed and stimulated by increases in cardiac knowledge and technology. “In technology in the treating of the heart, it’s just amazing. I think because it’s an ever-changing field of nursing too. It’s something you don’t get static in, you are always updating knowledge.” Essentially, Rae’s personal female-gender perspective equated treatment of the heart with technological knowledge. Yet, from a same-gender view, Carol Montgomery (1993, p. ix) viewed technological knowledge, such as heart implantation, as unimpressive and struggling to buffer the onslaught of chronic illness, which continues to debilitate human existence.

Similarly, knowledge and technology was enticing, from a male-gender worldview, to RN Rolf who chose cardiology because it was “something a little more interesting, a little more technical; and this is a nice compromise from being in intensive care, where the patients are tubed [intubated].” RN Amy expressed a similar life-project worldview, from a female-gender perspective; “Oh, I think because it is complex and there is lots to understand.” In contrast, I.C. Jarvie (1972, p. 55), a male-gender philosopher, argued the effective status of technological knowledge.
Yet technology is knowledge of sorts; such know-how as we have tells us about what works in this world. Its position in the structure of knowledge is thus peculiar, because what happens to be effective in our part of the world may be a purely contingent matter and will also depend on what degree of effectiveness we happen to demand of technology.

Indeed, the technological knowledge of heart implantation with an ICD is very much a contingent matter for the person who struggles with his/her vulnerability and mortality (Montgomery, 1993). While there is fascination in technological knowledge for cardiac nurses, regardless of gender, the person is dependent on the effectiveness of implantation with ICD biotechnology to sustain quality extension of life. Heart implantation knowledge is ineffective when it remains unshared. The lack of cardiac education for patients persuaded RN Lea to become “involved in cardiac education.”

I came over to [hospital] which has a lot of the chronic care of people with pacemakers and electrophysiology. Then I suppose it was a natural progression that the ICD patients would come into it as well. I also noticed that there was definitely a lack of education for these people. I was a very strong believer all along in education; empowerment through education for the patients. So I became very patient education focused. I noticed that there really was a greater need for patient education.

Lea’s female perspective in relation to technological knowledge in cardiology was similar yet different, in that her life-project encompassed “empowerment through education” for ICD patients. Unfortunately, not all cardiac patients would agree. In writing about her heart surgery, Australian writer April Hersey (1996, p. 40) commented on the same-gender cardiac nurse who rendered procedure education; “What on earth does she mean?” The concept of difference in relation to gender-perspective is evident in cardiac patient education booklets (Anderson, McAllister & Moyle, 2002). In the above excerpt Lea features “pacemakers and electrophysiology” and “ICD patients.” Cardiac patient education from a technological worldview is bound to evoke a response, such as April Hersey’s exclamation, of being lost in the technological information. Such is the nature of heart implantation with an ICD. The concept of difference featured as part of their perspective for several cardiac nurses regardless of body-sexuality/gender.

The difference in cardiology when compared to other nursing specialties had always interested RN Kay.
It is an area I have always been interested in and now I have been here for a while. I have never stayed in an area so long. I guess because every case is different. Every patient is different. They have different symptoms and different results. Just how it [heart] affects the whole system [body] for the patient.

Peter Raabe (2001) discussed the difference between the ways men and women develop their worldviews and knowledge. Men tended to respond to direct information, whereas women preferred discovery through various avenues to reach a similar worldview.

Even though Peter Raabe was making a generalisation, RN Adel’s female perspective inclined in a similar mode of thinking.

I think the main thing to say about that is it is something where you started looking after them [ICD recipients] and just that experience of different patients … that started to become your experience and skills started to develop, or even your lack of skills, because you had to start looking at gaining more information yourself. You know they are having this device implanted and you understand they have arrhythmias or quite lethal arrhythmias … this [ICD] is the treatment for them. I suppose you just try to gain more depth to your practice in treating these patients. You become a bit more holistic. Looking at other factors. So it has been a learning experience for me.

Conversely, as a male, RN Guy presented a similar perspective in relation to cardiology being different, yet male perspective that expressed “the multifaceted aspect of cardiology that really interested me.” Guy’s comparative perspective on cardiology patients and oncology patients also included the concept of difference.

I think there is so much … so many different aspects of it. Whether that be rehab, or interventional, or diagnostic cardiology, or heart failure, transplant … so it has been the multifaceted aspect of cardiology that really interested me. The other thing that is very attractive to me is that cardiology patients … generally they have the possibility of some form of recovery. With my oncology background I suppose you become very disheartened with people who generally end up dying on you.

Guy’s male-gender worldview embraced the possibilities of cardiology, which included the advanced technology from cardiac rehabilitation through to heart transplantation. Clearly, the difference in chosen activity lies within the fascination for technological solutions for the cardiac patient. The technological solution includes heart implantation with a permanent ICD. Thus, at this point of the chapter, the phenomenon of heart implantation has gathered meanings from cardiac nurses, who cannot be denied body-sexuality/gender. Similarities and differences enveloped a range of embodied perspectives that include: transcendence of personal fear; stimulation by technological
knowledge; something that was more technical and complex; technological education; technological difference; and in some instances, the cardiac patient was of secondary consideration to cardiac technology. Having embodied cardiology as their activity-in-the-world, which included the study phenomenon of heart implantation with a permanent ICD, I am persuaded that this group of participants have engaged with The Liminal Body. The term engagement is in no way pejorative, and includes myself as a cardiac nurse and cardiac researcher.

**IMPLANTATION AS ENGAGEMENT WITH BODY-LIMINALITY**

Synonyms listed for the word engagement in the above theme title include: embodiment, incorporation and responsibility (Dictionary.com., 2002). Engagement with The Liminal Body photograph and its visual impact embodies what it means to implant a person’s heart with a permanent ICD. However, do cardiac nurses and paramedical professionals understand what has been incorporated into their life-world? It befalls health professionals to take individual responsibility for developing as much understanding of the study phenomenon as possible; “I don’t think we understand exactly what people go through, having an ICD put in. I mean I don’t understand totally either” (Rae). The etymological origin of engagement is from the late Middle English ‘ingage,’ meaning to pledge something. During the 17th century the meaning expanded to: involve oneself in an activity (Pearsall & Hanks, 2001). Thus, implantation as engagement with body-liminality is to be involved with hybridisation of a person’s body and heart with a permanent ICD. Cardiac nurses attempted to portray how they perceived engagement with body-liminality from their threshold location. Laurie Spurling (1977, p. 28) explained the embodied perspective.

Indeed, my visual field, since it is animated and patterned by my phenomenal body which is oriented towards its tasks and interests at hand and engaged in marking out possible areas of activity in the world, is also a phenomenal field. Now the fact that my perception is embodied means that it is perspectival. If I attend to my actual perceptual experience, I will become aware that I only see ‘profiles’ of any object, that is, I see it at any given moment from one side at a time. Now, of course, subsequent perceptions can ‘fill out’ the perceived object as I move round it and view it from different sides and angles – nevertheless, at any given moment, I can see no more than my perspective allows.

RN Lea offered a concise account of her perspective in relation to “tasks and interests at hand” in the phenomenal field of engaging with implantation as body-liminality.
Certainly it is very frightening being taken down there and everyone is gowned and gloved and [person is] put on a hard table. The injections, then they put this thing [ICD] in. People are talking above them and around them and to them. But yeah, it is a very frightening experience for a person. There is a sense of powerlessness that happens. But knowing what is happening and how it is going to work; how it all works down there; why there are green gowns. They have an oxygen mask on. Knowing before they go in. I think it all helps with that experience and makes it less traumatic.

There are many existential barriers outlined in Lea’s account of heart implantation with an ICD. The cardiac nurse refers to the ICD as “this thing.” This appears as a dilemma on a pre-reflective level in engagement with heart implantation. The barriers of gowns and gloves locate both cardiac nurses and the person in liminal-necessity because this is “how it all works down there.” The mass of technology, that is heart implantation’s phenomenal field, renders the person afraid and powerless. Being aware of the person’s trauma places responsibility on the cardiac nurse. Thus, the cardiac nurse outlines the procedural barriers that will traumatise the person. However, the dilemma remains; being told of these unfamiliar barriers and contexts appears inadequate in allaying the certainty of fear and powerlessness that is heart implantation as body-liminality. Raabe (2001, p. 187-9) perceives this professional perspective as an unreasonable attempt at neutrality. Thinking the person “is knowing” simply because he/she has been told “can seem alarmingly remote, uninterested, apathetic, and patronising.” In their awareness of patients’ powerlessness, is it possible for cardiac nurses to “break out of a perspective that is causing [them] to be stuck in a seemingly unsolvable problem [dilemma]?” The phenomenon that is heart implantation was explored more closely.

**Being involved with actual perceptual implantation**

Most cardiac nurse participants in this study avoided giving their perspective on the actual heart implantation procedure. However, several nurses were willing to share their thoughts. RN Rae drew on her extensive experience as a cardiac nurse to ‘fill out’ her perspective of heart implantation with a permanent ICD and its context.

I suppose it is a cold area. That would be the first thing you would be conscious of. A lot of people gowned; you can only see their eyes. There are a lot of things going on around you and you probably feel vulnerable. Powerless, like I am in their hands; do I trust them? They are the things I think that would probably go through my mind if I were lying there.
The consciousness of being in “a cold area” sets the scene for heart implantation as crossing over the threshold into body-liminality. A person desires and needs body-warmth. Thus, a cold context was the first of many dehumanising sensations during heart implantation. RN Jody also recognised this coldness in her poem, Fire and Ice (Appendix H). The poem is a contrasting metaphor that personifies fire as the warm-blooded human heart implanted with the ice-cold metal ICD; “The fire of the person is being dampened because the heart is not working to potential. There is no longer that flame [of wellbeing]. The fact that the heart is at risk, the person is at risk. That cold thing [ICD] … having to accept a foreigner, and to rely on it.” Gowned figures unrepresentative of people, except for their eyes, add to the mystery of “things going on,” and heart implantation evokes vulnerability. Vulnerability leads to powerlessness and trust is questioned because of the context of heart implantation. Overpowering a person, already in a life-threatening, liminal void, can create body-sensations “so extreme that no human caring can assuage” (Gadow, 1988, p. 8).

Rae continued to reflect.

Lots of light. Strange noises. Things that you are not used to. I think the vulnerability is exacerbated because they will then come along and pull off the sheet. This exposes your chest while they put the drapes on. You sort of lose a lot of pride and privacy. While the staff are very reassuring and they explain everything as they go, I think people still feel very vulnerable. Perhaps even frightened about what is going to happen.

In this situation, senses become heightened because of tortuous lights, “strange noises,” unfamiliar “things,” and smells. In this liminal situation consistently referred to as “vulnerability,” the person is deprived of any thread of security attached to the covering sheet when it is “pull[ed] off.” Consequently, heart implantation becomes more of a reality as the chest is exposed. Being exposed and deprived of “pride and privacy,” even temporarily and with nonsensical “reassuring,” the Being within the physical chest is objectified. Merleau-Ponty (1962, p. 253) recognised deprivation; “To invert an object is to deprive it of its significance. Its being as an object is, therefore, not a being-for-the-thinking-subject, but a being-for-the-gaze, which meets it at a certain angle, and otherwise fails to recognise it.” Rae emphasised heart implantation as being “out of control.”

[Implantation] probably impacts on people’s self esteem, feeling that everybody is doing this to me and I don’t have any say. Like out of control. Well, not being able to have a say in what is happening. I think like someone who has had a stroke they can’t even wipe their nose because they don’t have any control.
Returning briefly to the word “chest” as being significant as the site of implantation and as the part of a person’s body where the heart is located. The etymology of chest is from the Greek ‘kiste’ meaning box (Pearsall & Hanks, 2001). Metaphorically, the heart, which is culturally treasured, is locked within a person’s treasure-chest. In terms of this treasure-chest, heart implantation “impacts” on “self-esteem,” renders the person invisible, “out of control,” without voice and, therefore, unheard. Jody interpreted her poem capturing the intrusion: “In the middle of this warm human being is this ice cold pond and it [ICD] needs to be there. The person didn’t ask for it; doesn’t want it, but they are paying [personal price] for it. It exists. The person has to put up with it or, um, the alternative is not the desirable thing.” Thus, heart implantation is disembodiment because the person is not in control of his/her body but is controlled by the protocols of the implantation procedure. The rules of control in the implantation procedure are forbidding and unforgiving, to use Rae’s analogy, in the event the person attempts to wipe his/her nose. In her awareness, Rae, as a cardiac nurse, is similarly a liminal captive of control because of her inability to cross the control boundaries (Lawler, 2002). Rae continued to relate implantation.

They have probably had some local anaesthetic from the physician. Then machines coming around them; the x-ray machine, fluoroscope. If they are claustrophobic, they are probably feeling quite hemmed in, unable to get away; a bit like a prisoner. Even if they are not claustrophobic they are probably feeling that. I think just that feeling of being imprisoned in that area and not being able to get away. They are conscious of smells, stuff that the drapes have been in and they have been sterilised. They have a smell about them. All that type of thing and they would probably feel quite nauseated.

Implantation imprisons the person within its insurmountable technology. These technologies of heart implantation include the pharmacology of anaesthetics, the machines, the drapes, the sterilisation, the smells, and each technology already mentioned. W. Norris Clarke (1972) argued that intended beneficence in developing technology tends to produce depersonalising and dehumanising effects. Principally, the negative effects are endured by those who are excessively subordinated by the technology, such as those involved in heart implantation with a permanent ICD. Being “imprisoned” in the heart implantation context is what Clarke (1972, p. 257) termed as “suppression of human freedom.” Thus, cardiac nurses’ engagement with heart implantation is a state of body-liminality because they are within the service of
technology rather than self-regulating solutions for the human problems that technological advances present. Rae expanded on how she felt about the person’s body under the drapes, the visible body-area selected for implantation.

It is just a part of the body that is being operated on. I don’t have any … I am able to switch myself off and just say, OK, we are putting in an ICD and that is here [body-part]. I am not sort of feeling, oh, my goodness they are cutting through the skin or anything like that. I am able to just see it as a procedure. Put in an IV or something, it is just something you do.

Writing about his life-threatening experience of procedures in ICU David Rier (2000, p. 73) stated; “In this I was alone.” He felt defined in empirical terms, with health professionals gazing at an array of technology as a priority before acknowledgment of his person. He found this situation disconcerting and incomprehensible because he felt competent in communicating how he felt. Thus, heart implantation is defined as engaging with body-liminality because the cardiac nurse is “able to switch myself off,” and “to just see it as a procedure.” In other words, the cardiac nurse is disengaging and detaching from the person during heart implantation. Disengagement removes the cardiac nurse from the person and displaces both in liminal-aloneness.

Rae also confirmed that the focus was primarily the implantation procedure of the ICD.

I suppose for the person inserting it [ICD] … it does to a great degree. But they would also be conscious of monitors, breathing patterns, communicating with whoever is [there]. They always have an anaesthetist there even though they don’t always have a full anaesthetic. So yeah, communicating, looking at obs[ervations], what is the blood pressure now, what is happening on that screen, and where are we with the wire? I suppose they are fairly well focused, they are taking in the big picture as well as the little picture.

With no mention of the person’s subjective-body that has been depersonalised with many descriptors, such as imprisoned and out of control, he/she becomes submerged beneath preoccupation with technological apparatus. Thus, heart implantation as engagement with technological-body-liminality reveals itself to be irresistible. Rae’s dialogue portrays cardiac nurses’ consciousness to be of “monitors, breathing patterns, communicating” with medical personnel, “looking at obs” such as blood pressure readings, and the fascinating screen that shows “where are we with the wire [pacing wire].” The word “we” signifies group engagement with and preoccupation with the implantation procedure. A question about the person under the drapes breaks the big
technological-picture. Is it feasible that focus can be divided between the person and the technology and yet both receive full-attention? Rae continued.

Well, from my experience, most of the staff that I have worked with in that area have always been conscious of the patient. They will ask the patient, are you feeling OK? Is everything alright? Are you warm enough? It won’t be long now. Do you have any pain? Sort of just how they are feeling and how they are dealing with it. And reassuring them that they are a body … not a body [difficulty here] … a person under there, and they are not being forgotten while all this is happening.

My dual perspective as a cardiac nurse and as a person who experienced EP studies and cardiac ablation, contrasts with Rae’s statement. Without any warning I lost consciousness during the six-hour procedure. No doubt this was a vasovagal episode. On regaining consciousness I signalled to a cardiac nurse who was watching the screen and told her, “I lost it [consciousness].” Her immediate contradiction, “No, you didn’t,” was not “warm,” concerned, or “reassuring.” I remember a feeling of dismay and dismissal. My claim was not documented. Losing consciousness is not something a person imagines. This was not an isolated incident. During a second procedure of cardiac ablation I experienced left-arm radiated pain and again told a cardiac nurse. Time passed and the cardiologist continued with ablation until I signalled him that I was in distress. His response, “why didn’t you tell anyone,” was curt and nullifying. The cardiac nurse had left the area.

As a cardiac nurse and cardiac researcher I know these experiences are not isolated and are in need of expression. As mentioned in the previous chapter, nurses may choose not to care, but negative meanings may result in cardiac nurses choosing to disengage from patient involvement (Montgomery, 1997). Rae moved on to the defibrillation phase of heart implantation when the patient is control-shocked for purposes of testing the ICD.

It always gives me a bit of a shiver. It makes me a bit goosy. Just because I think that was an electric shock. There is always a convulsion. It is probably not as dramatic as when you have a patient in an arrest situation. That to me is always more spine tingling. I have to give them a shock there and then, because the adrenaline is rushing and everybody is sort of on edge; save that body, come what may. [Conversely], in the procedure of an ICD, it is more of a controlled situation. (…) It is just part of the procedure.

Thus, the person enters hybridisation and body-liminality through electric shock and the throes of convulsion. It is “spine tingling” science reality. Philosopher, Nicholas
Berdyaev (1972, p. 209) argues that the hybridisation of body and technology deals a terrible blow to emotionality and human feelings. Biotechnology “endangers the heart, which can scarcely bear the contact of cold metal and is unable to live in metallic surroundings. The process of the destruction of the heart as the centre of emotional life is characteristic of our times.” Defibrillation is a dilemma for many cardiac nurses. I have witnessed many physical reactions from cardiac nurses during an in-hospital cardiac arrest; the most severe being the inability to securely hold fully charged defibrillator paddles because of anxiety. The distressing pressure to be engaging with “save this body” is very real in the clinical setting. RN Lea responded when asked what implantation meant to her as a cardiac nurse.

Having a device, a metal device put into their bodies and it is designed to do a function and in this case it is an ICD. It is designed to defib them out of a life threatening situation and all that goes with that, such as the surgery, all the procedures, the pain involved, and the uncertainty of it all comes into the term ‘implantation.’ (Another word for implantation?) I don’t know … I don’t know that.

Lea was unable to step outside her clinical perspective, which encapsulated implantation as engagement with body-liminality. However, “uncertainty” was similar to Jody’s descriptor, “intrusion.” Jody’s interpretation aligned with Nicholas Berdyaev’s perspective.

It is the thought of having something artificial inside the body. Everything that the heart represents to the person is being threatened, physically, emotionally and spiritually. The absolute, sheer terror of having the heart tampered with. Intrusion is … the person did not ask for it [ICD].

Jody’s phrase, “having the heart tampered with,” suggests that this is the immediate point of jeopardy for the person. A synonym phrase for “tampered with” is “being altered” (Pearsall & Hanks, 2001). Philosophical counsellor Shlomit Schuster (1999) drew on philosopher Emile Durkheim to point out that it is a person’s altered state of self rather than the circumstance that causes “absolute, sheer terror.” How cardiac nurses and others enter into relationality with a person’s altered body-state emanates from their perspective on extending life through hybridisation of heart and ICD.
IMPLANTATION AS BODY-RELATIONALITY

In the phenomenon of heart implantation with a permanent ICD, cardiac nurses engage with people who are to have life-extension. In this engagement, it is imperative that altering the heart is comprehended by cardiac nurses through the person’s understanding and experience. How does the cardiac nurse deal with implantation as body-relationality? Heart implantation is a medical science hybridisation; a circumstance which neither the person nor the cardiac nurse created. In forming a helping relationship it befalls the cardiac nurse to be an unambiguous and authentic communicator. However, RN Adel realised the difficulty in her role as a cardiac nurse. “I do know I am damn well not an equal partner in cardiology. Nobody is ever going to listen to my concerns. My concerns would just be, how can I actually be of appropriate help to the patients receiving them [ICDs]?” Merleau-Ponty (1962, p. 354) captured body-relationality as an encounter with another Being.

In the experience of dialogue, there is constituted between the other person and myself a common ground; my thought and his[her] are interwoven into a single fabric, my words and those of my interlocutor are called forth by the state of the discussion, and they are inserted into a shared operation of which neither of us is the creator. We have here a dual being, where the other is for me no longer a mere bit of behaviour in my transcendental field, nor I in his[her]; we are collaborators for each other in consummate reciprocity.

RN Sue’s perspective reflected a collaborative approach with patients in relation to implantation as body-relationality.

The first thing I really do is to ascertain where they are coming from and where they want the most information. Do they want to know about the procedure, or do they want to talk about how they feel about having it done? You’ve got to go where the patient is at. And if their, ah, main problem is anxiety, then we need to deal with that before we start talking to them about having incisions in the collar bone and that sort of stuff. So often they are hanging out, when I get to the bed. I say, “I understand the doctors are talking about putting a defib into your body and I just wanted to talk about what your understanding is of what has been happening and what is going to happen. See how you are going with it all.” That would be where I would start.

Sue recognised the responsibility of her role as a cardiac nurse by the acknowledgement of a person’s Being-in-pain. Pain is not a pathological response alone (Taylor & Wilson, 2000). There are many elements to human pain, such as wanting “to know,” wanting “to talk,” “their main problem is anxiety,” “about having incisions,” “hanging
out” emotionally, and the trauma of the cardiologist “talking about putting a defib into your body.” Acknowledgement of the person’s pain in relation to heart implantation with an ICD demonstrates a knowing presence in body-relationality. Acknowledgement may assist with the utter aloneness of existential-pain that “belongs in a unique way only to me” (Illich, 1976, p. 147). RN Guy’s perspective involved engagement with body-relationality by acknowledgement of liminal-trauma.

I think we reinforce a lot of their trauma that they have experienced with their cardiac arrest in the community. We do refer to their diagnosis here as sudden death syndrome, so yes I do think we reinforce that; and that the person had died and been resuscitated. My experience is as well that if some of these people have had some ‘down time,’ they may have some neurological sort of hypoxia as well for several days after they come into hospital; short-term memory loss. So there is not the reception of what we are telling them. It is not fantastic by any stretch of the imagination, so they are very much impaired to start with.

Knowing and acknowledging the person’s Being-in-pain, the dilemma for the cardiac nurse is exacerbated. Medical terminology tends to “reinforce a lot of their trauma.” This raises the question of whether the term “cardiac death” serves to reinforce a belief in the ICD as “life-saver.” Nonetheless, the cardiac nurses’ dilemma is proceeding with offering life and death related information to a person lacking “the reception of what we are telling them.” Thus, heart implantation as body-relationality was “not fantastic” in a “very much impaired” person-centred circumstance. Guy acknowledged trauma-extension inflicted on family members.

We place a lot of the initial education and a lot of the pressure I suppose, on that person’s family, or their spouse. They are experiencing a lot of the overload of information that we are giving them, by focusing our efforts onto them. They have been there, their relative or spouse, in the arrest situation, where they have been resuscitated. They may have done the resuscitation themselves. And then we are burdening them I suppose with all this information about this device that we are going to implant. It is a very difficult time for the person who is going to receive the ICD, and their family. I try to be very gentle with the people and keep what I tell them really, really basic.

Heart implantation with a permanent ICD is a medical decision as Guy was aware; “we [cardiac nurses] just reinforce what has been given to the person and their family. Yeah, it is a pretty tough time.” Without any decision-making involvement cardiac nurses struggle with the dilemma of placing “a lot of pressure,” “overload of information,” “burdening them,” and engagement with “a very difficult time.” Beauchamp and Walters (1999) discussed the dilemma inherent in a situation as
alternatives that are desirable in many respects yet unacceptable in other respects. Guy’s dilemma with implantation as body-relationality persuaded him to be “very gentle” and “really basic.” Cardiac nurses can be ambivalent and negative about involvement when a person is “really legitimately upset.” In contrast, RN Fay’s cynical perspective entailed the belief “that over half the problems we fear are because the person has induced them upon themselves. Peoples’ stupidity amazes me all the time. And that is a scary thing. People scare the hell out of me.” After listening for some time I asked Fay whether she felt that some patients “fall through the cracks.” Fay was honest yet uninvolved.

Um, I don’t really know about that. I don’t get involved with it. But um, there are lots of things that fall through the cracks that um, you sit there and think, well, maybe that should never have happened; all those sorts of things. I don’t really worry about it.

The perspective of the cardiac nurse determines the effectiveness of body-relationality in engagement with a person experiencing the study phenomenon. In the liminal circumstance of heart implantation, effective body-relationality cannot depend on the person’s interpersonal abilities to engage with the cardiac nurse. Meaningful engagement “goes beyond these superficial manifestations of self to recognise the universality of the person’s humanity” (Montgomery, 1993, p. 83). RN Gay related her perspective.

It depends on the educator, and now that is a problem, because if I say I think I educate them very well, that is just my own perception. Now that is not good because this morning I can’t talk to a patient for an ICD. He has actually told me to get out of the room. So this is an unusual thing to happen to me, to be told by a person to go, he doesn’t want to talk to me.

Gay’s self-descriptor is “educator.” In modulating a person-centred relationality the clinical approach appears contrary to Carol Montgomery’s notion of moving beyond superficial perspectives of self. Gay’s patient had a different first language and a different culture. His belief emanated from his mortality; “I don’t need this [ICD] because I am going to die.” However, Gay invalidated his belief by stating; “No. We are going to put this device in to help save your life.” In counter-commanding the patient’s belief, Gay evoked negative engagement with body-relationality; “He went off and said, “I understand you perfectly, but you just don’t want to understand me. Go away, I don’t want anything to do with you or this [ICD] or whatever.” RN Amy
expanded on the complexity of the cardiac nurses’ dilemma in attempting to make a connection within the liminality of implantation as engagement with body-relationality. They are generally in quite a lot of shock when they come here and they have either had a major heart attack or some large life-changing event they did not think they would have. They can be depressed or a little bit withdrawn or they are voicing their concerns; “I am going to die or I never thought it would happen to me” sort of thing. (…) I do a lot of patient education and quite frequently they say, “oh, you know, they never told me that.” But I think it is because they are so stressed that they really just can’t take it in. Now when you did tell them and you documented what you have gone through, they are thinking of a hundred other things, like, am I going to die or what is life going to be like? Because they are so afraid, they don’t actually take a lot of that in.

The insight and understanding that cardiac nurses contribute in engagement with a person in body-relationality can make a difference. A person’s struggle within the “existential vacuum,” or body-liminality, is a search for the meaning in life and the meaning of life, as it is perceived in his/her situation (Raabe, 2001, p. 105). Most cardiac nurses in this study ‘know that’ interaction with their patient influences existential meaning, but to ‘know how’ to make those interactions meaningful can be a dilemma (Stein-Parbury, 1996). Cardiac nurses dealing with “shock,” “depressed,” “withdrawn,” “concern,” questions of dying, and “a hundred other [existential] things,” require the wisdom to ‘know that’ the person is the educator in relation to ontological problems, such as his/her mortality.

In contrast, physiologist Roy’s perspective focused almost entirely on reinforcing implantation with the ICD. “Reassuring that it [ICD] is a life saving device. Without it, the alternative isn’t worth thinking about. The doctors made a decision, that is the best scenario for yourself.” I pursued body-relationality and the ‘know how’ situation with an interactive question on how Roy would assist me if I were not happy with the prospect of heart implantation. He was perplexed. “Assist you? You are not happy about having it inserted? I haven’t come across anyone like that before. I don’t know how I would approach them.” RN Kay’s response to the same interactive question was similar yet different.

Um, maybe they are not told enough. I mean, sometimes they go to their local doctor, the local doctor refers them to a cardiologist and it is more or less the cardiologist has sent the letter here. Maybe down that end it is not explained to them well enough, I don’t know. I don’t know whether it is just a personal thing. It just depends on the patient.
Kay’s response indicated an absence of understanding and responsibility in body-relationality as a cardiac nurse. In cases of life-threatening illness, cardiac nurses and other health professionals may disengage from the responsibility of engagement with body-relationality in seemingly innocuous ways. Alan Radley (1999) wrote of these innocuous disengagements, such as the bed-sign that informs other health professionals of a procedure without any explanation for the patient; the absence of the nurse who would provide support; and information impersonally given in the form of a booklet or a video. Thus, for some health professionals in this study, implantation as body-relationality did not hold existential meaning within their perspective. However, psychologist Rick voiced a sound fundamental understanding of implantation as body-relationality. He realised and acknowledged his interaction with “their whole world being turned upside down.”

After a while, I certainly started to discover (...) very profound changes had happened in people’s lives. They had almost gone to heaven or wherever. But they had been brought back. Now that for some of them was a pretty defining sort of event and then everything else changes. Suddenly, the rules of the game, their whole meaning of life changes. So that is a profound event for a lot of people. Suddenly, it affects their priorities in life. It affects their relationships in life. Suddenly, everything that is taken for granted, is no longer taken for granted. It is as if you’ve got to ask all the questions again. What’s the purpose of getting up in the morning? Why am I here? What does it mean, that I was dead but now I’m alive? Pretty awesome stuff. Some are really grateful of that. Sometimes they don’t easily come back and do the ordinary things because the ordinary things are no longer. They are different. Everything is different.

Implantation as engagement with body-relationality involved Rick during research on the effects of ICDs on recipients. The objective of this research was “in terms of the amount of reimbursement that [cardiologists] they could claim for these machines.” During Rick’s engagement with recipients he “certainly started to discover” what Merleau-Ponty (1962, p. 179) described as; “Taking up of other’s thought through speech, a reflection in others, an ability to according to others which enriches our own thoughts.” Rick’s account of his philosophical perspective demonstrated his understanding that empathic body-relationality was one of trustworthiness, support, “desensitisation by sharing the problem or question” of lived-meaning, and person-centred collaboration (Schuster, 1999, p. 16). Another significant aspect of body-relationality was engagement with the ICD by cardiac nurses and other health professionals in this group.
Being incorporated with the ICD

Thus far, cardiac nurses and paramedical professionals have stated their perspectives in relation to The Liminal Body, hybridisation of person and the bioelectronic ICD. In liminality, relationships involved are existential and I-Thou; liminality is “essentially ambiguous, unsettled, and unsettling” (Turner, 1974, p. 274). I-Thou (Buber, 1970) is a philosophy of the way people relate to their world. Moments of body-relationality entail being available to another person, attempting to understand their situation. I-Thou body-relationality enables true dialogue and true sharing. How does this group view being incorporated with ICD-liminality? Part of the derivation of incorporated is having a bodily form, embodied (Pearsall & Hanks, 2001). Psychologist Rick believed the ICD to be a “neutral” bioelectronic device until it is incorporated, embodied, or heart implantation occurs. Participants in this group were asked questions such as, “Would you have an ICD?” and “What does the ICD mean to you?” RN Adel’s perspective was influenced by body-relationality.

Um, I really do think I would. I think if I went through that experience, I would be tempted to have one. I imagine the experience is a near death experience. It would have a pretty high impact. I know once you get inside those experiences your survival instincts take over. And when you are presented with something that helps guarantee your survival, you are very open to it. So I think I probably would. As a healthy person I feel dreadfully sympathetic to people who are in that situation, because I know just how life changing it would be, to me anyhow. I might be over dramatising it. But that is how I feel. I have three children. I am better off to my kids alive, than dead. People have to make these choices for all different reasons. I would be irresponsible not to. For me, if I were offered that type of treatment, it would be irresponsible not to accept it.

Adel acknowledged the “high impact” of “survival instincts” that influences a person’s state of mind when confronted with a “near death experience.” Adel was prepared to embody ICD-liminality in spite of its dreadful, life-changing, and dramatic aspects, because of the choice that was unique to her life-context. Adel admitted she would possibly lapse into a “depressive state” but her moral responsibility was to remain alive to care for her three children. The body-relationality of this situation is that self-interest is put aside because of the I-Thou-otherness of children’s vulnerability is irreducible to most parents (Levinas, 1993). RN Lea expressed her incorporation of “a person’s heart being implanted with a metal bioelectronic device” as “fantastic.”
I think it is quite neat. I think it is really terrific that this device is there for them. And if it was me in a situation, I think it would be great that this can be done and I know it doesn’t interfere with the heart. I just think it is a terrific device and I don’t have any problem with it being implanted into someone, or including it if I had to, myself. It is fantastic. I think it is incredibly clever. I know it is such a simple word, but it is very clever technology. I think with ICDs, if it is used appropriately, I think that it is a fascinating science and I don’t have any problems with where it is going.

Within the same dialogue Lea ‘flipped the coin’ and related to the ICD in a less positive context.

Oh, I guess it [ICD] is not a lot of things. It is not the be all and end all. I guess in some respects it is not a life-saver. It is not a pleasant thing to have to have. It is good that it is there to have but it is not what you would want to have. It is not a cure it is a symptom management device. Sometimes it is not the solution either. I’ve only known one person who has had their implant taken out, because they couldn’t live with it. So it is not always the solution to the problem.

The preceding dialogue demonstrates the potency of effect that emanates from biotechnology. It captures the imagination as “neat,” “terrific,” “fantastic,” “fascinating,” and “very clever” technology, yet “it is not a lot of things” including heart implantation that a person “could not live with.” Implantation as body-relationality can be adverse to the extent that explantation is preferable. Heidegger (1977, p. 4) recognised the seductive quality of technology long before ICD biotechnology was developed. “Everywhere we remain unfree and chained to technology (…). We are delivered over to it in the worst possible way when we regard it as something neutral, for this conception of it makes us utterly blind to the essence of technology.”

Psychologist Rick experienced difficulty in stepping outside his clinical worldview of ICD biotechnology as “a wonderful device, a lifesaver.” By deduction, which he expressed as, “That is a hard one [question],” Rick concluded.
It can’t fix all the things, all the issues surrounding the need for it in the sense of the effects that the heart condition has on people’s lives. The ICD is like most technology if you look at it in that sense it is neutral. It has no opinion as they say. It is a device, but its implantation and then what it does to people of course is not neutral. It has impact. So implantation of course I think it adds another dimension that people have not had any experience of. I think it does affect the person’s relationship with their body. It just alters it [heart] in a way that we are not used to. So I think it does affect how we feel about our bodies and our sense of being in charge of our bodies, our sense of fragility, that sense of certainty. That sense of fragility, that sense of things could be taken away at any time, that constant, potential sort of teetering on the edge can become as issue.

This area of implantation as body-relationality was a philosophical concept that Rick had not contemplated in his previous associations with ICD recipients. In considering body-relationality he referred to “The Six Million Dollar Man, or The Bionic Woman. Just that little bit of sense of somewhat … that humanness or a little less human. Something not quite completely human.” Body-relationality inspired Rick to move into the concept of cyborg or hybridisation.

There is going to be more and more of this ‘add on’ impact. If we take it back [in history], this ICD is just part of a long line of that. Whether you get your hip replaced or pins put in our joint, it is all technology that is added that has that cyborg feel about it. We are moving onto smart machines and now starting to become implanted. That is what the new generation of these ICDs do. They not only sense, but they react. They not only react, they monitor, they feedback. You can just start to have a sense that this is the beginning of all sorts of other things that are going to be implanted and added on, connected to, wired up, who knows where it is going to end. I think it is going to have an impact in that, it is going to change the way we experience others and ourselves. It is really going to change the nature of people.

The concept of cyborg or hybridisation fits with “that constant, potential sort of teetering on the edge” that is another way of defining liminality. While Rick used descriptors, such as “cyborg, smart machines, implanted, sense, react, monitor, feedback, added on, connected to, and wired up,” Rayna Rapp (2000, p. 184) referred to unstable technological applications as “resculpted” and Joseph Dumit (2000, p. 209) focused on patients affected by “new socio-medical disorders” induced by new biotechnologies.

Incorporating the ICD evoked a contrasting response from RN Guy.
That’s a good question (laugh). Um, I think I said this was their insurance policy. Um, I think it is not a cure. And I also think it is not an absolute. I have known of people to have multiple therapies delivered from their ICD. And they still have died, so um, … I don’t know that we go as far as to say, now you are superman or superwoman … [you] cannot die. But certainly there is the potential for that to be seen.

The metaphorical “insurance policy” of being the original “superman” in the film classic of the same name, meant little to Christopher Reeve (1998) who struggled with the possibilities of embodiment and finally with the potentiality of disembodiment through the lack of body-relationality in quadriplegia. Likewise, heart implantation had conflicting meanings as body-relationality when incorporating the ICD. RN Sue perceived the ICD as an unwelcome “constant presence” yet also as “something like a guardian angel, or a knight in shining armour.” RN Amy thought, “For a lot of people they [ICD] can mean a new life, whereas for a lot of other people they can mean … hideous. A hideous life.” RN Gay decided, “If I thought there was a chance of my falling down dead from VT or VF, yeah I probably would [have an ICD].” RN Fay was one of only two participants in this group who definitely stated, “I thought about this one. And I thought, well, I don’t think I would [have an ICD]. It is a huge dilemma.” Possibly it was also a huge dilemma for those participants who talked around this issue without being as direct as Fay.

From these contrasting and ambivalent body-relationalties, the I-Thou-other entities become separate and liminal. The “potential and power of a technological device to shape an interaction is not a pre-given” but is determined by the perspective of the person who is both a health professional and a Being (Timmermans, 1998, p. 148). RN Amy was the second cardiac nurse in this study whose perspective denied being incorporated with the ICD. “I think it would be catastrophic. It would be very hard. Like, you see the way they [patients] are. I wouldn’t like to have an ICD. Not very nice.” Timmerman’s concept on a technological device, such as the ICD, can be applied to the conscious awareness of cardiac nurses and other health professionals in engagement with implantation as body-emotionality.
IMPLANTATION AS BODY-EMOTIONALITY

Participants in this group as Beings-in-the-world cannot be assumed to be devoid of body-emotionality because of their engagement with bioelectronic devices, such as the ICD. While Merleau-Ponty (1962, p. 154) acknowledges “The objective [technological] world plays less and less directly on the keyboard of ‘elementary’ affective states, their value remains nevertheless as a possibility of pleasure and pain.” He also acknowledges the possibility of “the act of transcendence” over technology. “If then we want to bring to light the birth of being for us, we must finally look at that area of our experience which clearly has significance and reality only for us, and that is our affective life.” RN Rae expressed conscious awareness of body-emotionality.

They look at you rather astounded. “You don’t know what I am going through.” I am very conscious of the emotional turmoil they are going through at that time because I have been there and done that and I know how I felt. I thought it was the end of the world for me.

Rae brought to her clinical practice the personal experience of family heart disease and the personal threat of having invasive cardiac procedures. “Oh, I was terrified. I was convinced I was going to have open-heart surgery. I cried for 24 hours. The girls in CCU thought I was mad: she is having a nervous breakdown. So that then allowed me to say: “yes, you will have these high emotions.” However, patients remained “astounded” at her claim to understanding because their subjectivity about their own specific circumstances was the issue for them. Nonetheless, Rae’s perspective is meaningful to this study. As a unique Being Rae anticipated liminality, the end of her lived-world and the beginning of mortality. Patients would have experienced these same tumultuous emotions together with feelings of astonishment at a cardiac nurse’s claim to understanding what they were “going through.” While Rae was removed from her clinical mode, there was the opportunity to expand on the belief underpinning her terror and tears.

To me, the heart is probably very close to the soul. It is. While it is the thing that keeps me alive or helps to keep me alive, I see it as the centre of a lot of emotion. Even the centre of feeling, it is how you are feeling. And we say, oh, I did it with all my heart. We talk about those sorts of things and I just see it very much as heart and soul going hand in hand together; sort of like the central being of my body.
RN Jody expressed a similar belief in her poem Fire and Ice, “Against my soul.”

Referring to a private corner, and what the heart means to the person, the emotional, spiritual being and the invasiveness of it [ICD], sitting up against the essence of the person; this guest of necessity. The way they are now thinking of their heart, the changes for them.

While Jody’s poem adds meaning to Rae’s perspective, Merleau-Ponty (1962, p. 151) adds meaning to the impact that a poem and a person’s body are analogous as works of art. “A novel, poem, picture or musical work, are individuals, that is, beings in which the expression is indistinguishable from the thing expressed, their meaning, (…). It is in this sense that our body is comparable to a work of art. It is a nexus of living meanings.” Thus, the nexus of a work of art is comparable to the belief in the heart as the “central being of my body.” Other cardiac nurses held similar convictions.

RN Lea expressed that she had been asked “some really good, very intuitive questions there. It has given me a lot to think about too.” Hence, Lea expanded on what meaning she ascribed to the heart.

Yes. I think the heart is a vital organ. Both what it does physically, so it is a pump and it pumps blood blah, blah. But it is also, in our society, it is a very important organ in the fact that it expresses our love for people. We almost … it is an essence. We use it as a symbol of who we are. So, I mean, my heart on my sleeve; I love you with all my heart. I think socially it is a very important organ. I think that is where a lot of the trauma comes from when people have something that goes wrong with it. It is the fact that it touches them not just physically but emotionally it really gets them. It challenges their very being if that makes sense. I believe in that and I see that a lot.

Lea expressed some important ideology in her dialogue; “expresses our love;” “an essence;” “socially” important; “trauma;” “touches;” “gets them;” and “challenges.” Arlie Hochschild (1983), in his aptly titled work, The Managed Heart, drew attention to how the feelings, emotions, and subsequent actions of a person are tapped into and socially engineered because of social meanings. For example, this dialogue took place close to St. Valentine’s Day, the symbol of which in the Western world, is a heart-shape signifying love for spouses, lovers and significant others. Thus, for many people heart implantation with a permanent ICD is especially emotional. Physiologist Roy had similarly never taken part in a phenomenological dialogue. “I guess it has made me think a little more closely about how I deal with this particular client group. I have never really taken a step back and thought about it in detail. It is quite an eye opener.”
His perspective on the heart was also similar to Lea’s perspective and he acknowledged other cultural belief about the heart. For example, in Tahitian culture the belief exists that the black pearl is the symbol of hope for the wounded heart (http://www.tahiti-blackpearls.com/, 2003).

I think its interesting how different people and different cultures and even different races think of the heart. The vast majority of people claim it represents the soul and once the soul has been damaged it changes people’s lives forever. They become mortal, they become fearful that they are more aware of their mortality.

Emotional idiomatic phrases, such as ‘the heart of the matter,’ and those expressed by Lea, are frequently used for the purpose of not wanting to be labelled as too emotional in a particular context. Stephanie Shields (2002, p. 179) used an emotional idiomatic phrase to entitle her work, Speaking From The Heart, in which she discussed the flexibility of emotion language. Shields demonstrated her point by drawing on the words of a song titled Emotional Girl.

Some folks say I’m too extreme
‘Cause I can’t stop once I start
But I never could do anything
With half my heart.

This raises the question whether cardiac nurses and other health professionals are uncomfortable with the “connotative baggage” (Shields 2002, p. 179) that goes with being emotional. While RN Amy acknowledged patients “feel it [emotion] from the heart,” she knew “it [heart] so well in a clinical way that I can’t get past it,” RN Gay also expressed a “comfortable” clinical mode.

I do try and stick to medical terms as much as possible. I am comfortable with that. At the end of the day when you go to educate this patient, you are telling them they are prone to dying. I can’t get round that, no matter if I dress it up or dress it down. This is a job I am doing. It is not my life. I have my own life to lead. I am very careful of that once I leave the hospital. I don’t take this with me.

RN Rolf was momentarily embarrassed when asked for his personal perspective on the meaning of the heart.
(Laugh). Not sure how to answer that question. I know it all backwards from
the clinical perspective. From a social and psychosocial perspective, I saw a
married couple die. One died from a heart attack and the partner died from a
broken heart. They curled up and died within two weeks of each other,
readmitted to our unit. So there is a strong emotional link to the heart and to the
patients. And to see how it affects them, it is a difficult question to answer. It is
gob-smacking that this partner just curled up and died within two weeks of their
partner dying. And they literally did, there was nothing else.

Historically, culturally, in literature, and in art, the concept of dying of a broken heart is
a powerful belief. The loss of a spouse is a significant factor in what psychologists
recognise as ‘the broken heart phenomenon (O’Conner, Allen & Kaszniak, 2002).
There was evidence that all participants in this group experienced emotional dilemmas
in relation to implantation of a person’s heart with a permanent ICD.

**Being-in-the-emotional-world of dilemma**

An emotional dilemma for cardiac nurses and others is the confusion of being between
the significance of subjectivity and the rational/technical of objectivity. Merleau-Ponty
(1962, p. 213-215) argued, “We must re-examine the dilemma of for itself and in itself,
which involved putting ‘significances’ back into the world of objects and freeing
subjectivity,” and “We must stress this point. How have we managed to escape from
the dilemma of the for itself and the in itself, how can perceptual consciousness be
saturated with its object, how can we distinguish sensible consciousness from
intellectual consciousness?” Psychologist Rick was aware of the dilemmas associated
with implantation.

The ones who have access to this technology are going to communicate in a
fundamentally different way and a different level. It is going to be a completely
different potentiality that might just be a little science fiction. Once upon a time
people just died, we just accepted it. It was inevitable. It was everywhere. Now
death is going to become even more remote. It is going to become so precisely
refined that maybe it will be an X number of years that we are actually given.
We will know when we are going to die. I mean this is *whoa*! Maybe there are
some things we don’t want to be able to control. We’ve got a huge ethical
dilemma.

Rick was questioning the fundamentally different potentialities of altering the lifespan
of a person through present [the ICD] and future biotechnologies that redefine the
significance of dying naturally. In this way, the notion of significance becomes withheld in the control of science reality. Peter Verbeek (2002, p. 2) agreed with philosophers like Heidegger in understanding technology as a paradigm that patterns the way people, including health professionals, live their lives and enter into engagement with devices, such as the ICD. “Whereas technology promised to disburden and enrich people’s lives, in fact it takes away people’s engagement with reality,” in relation to controlling life and death to a specific moment. Technological control is what Rick felt as an emotional dilemma. RN Rae expressed a similar view.

I have to admit if I had an ICD … I constantly have to question. Are we playing God? Who are we to play God? Is not there just a time to die? While I might not feel that this is what God intends, who am I to question that anyway? I am in a field where there is incredible change, incredible events in technology.

RN Adel also expressed concerns.

My feeling is they are putting in more and more [ICDs]. Are they going to slow down and perhaps re-examine some of the cases to whether they really need an ICD, or even should have an ICD? Those questions do concern me.

RN Sue felt the dilemma of responsibility when her role, in relation to implantation, caused trauma to the patient.

My job was to stand there with a paddle, beside the patient and talk to the patient and then put the paddle on the chest to discharge if they went into VF. Then try to keep them calm when they came thrashing out of their arrest. It was … it was like watching something out of a horror movie. You could almost smell the flesh and it was just horrible and he was so sore. It [person’s body] was like contorting. I felt horrified. I felt responsible.

The emotional dilemma for Sue involved the paradox of wanting to be there to “calm” patients in a life-threatening situation yet at the same time knowing her presence was the instrument [paddle] to contort their body with electronic discharge. Emotional dilemmas concern the notion of what the fundamental meaning entails to be a nurse in a life-threatening procedure. There is a value judgement of not only commanding technical expertise but also empathy for patients and courage to do what is medically expected (Killen, 2002). Sue also felt an emotional dilemma in voicing her moral responsibility in engaging in a “horrible” situation. “I probably think I wouldn’t have a job if I did that. I think I get enough flack. Let alone if I dared to suggest to the patient that they take time to think about whether they think they should have their ICD put in or not.” RN Kay held a similar view; “Um, it is hard to … some nursing now you feel
like you are more a resident doctor. I think there is a lot more put on nurses. More responsibility.” I pursued emotional dilemma with other cardiac nurses. RN Guy was hesitant.

Right. Um, (silence … great difficulty) the person might be unconscious or they might be conscious. And to see them have a shock, the person might be really quite agitated and frightened because they know what is about to go on. And to actually see them jump, um, I think I feel fairly relieved really, when I see somebody having a shock. Because my immediate thought is, thank God, the thing [ICD] works. It works. [It] sounds quite bizarre really, doesn’t it? (nervous laugh)

The dialogue between Guy and myself was via the telephone. Although gauging facial expression was impossible I appreciated his silence and undoubted reflection upon engagement with implantation. Guy’s emotional dilemma revolved around being assured that his role as a cardiac nurse was validated; “thank God, the thing works.” While Guy felt his feelings of relief were “quite bizarre,” the expression of his emotional dilemma was “being true to emotional self and authentic in emotional exchange with others” (Shields, 2002, p. 169). RN Rolf was more questioning about implantation; “We use everything we can to keep people alive. I think that while it is very important and very appropriate, it needs to be moderated with common sense, and a little bit of ‘is this the best thing for the patient?’ Yes we can do this and … but should we do it?” Alan Barnard (2002) advocated nurses to be more questioning of technology and to engage in more examination of epistemological, ontological and dilemmatic challenges arising from technology. This included benefits for patients and more appropriate outcomes. RN Amy expressed concern in relation to the emotional dilemma of implantation. “I think a lot of the time they [cardiologists] are very … they put ICDs in too quickly rather than trying medical therapy first. Well, I feel really sorry for them [recipients] because they have not … they really don’t know what is coming for them.” In explaining the differences among various emotional dilemmas, Leonard Berkowitz (2000) noted that when blame was involved the emotion most likely was anger. As a cardiac nurse, possibly Amy was both angry at inappropriate heart implantation and sad for her patients not knowing enough to have control of the choice.

Emotional dilemma expressed by RN Rae included technological advancement as a potentiality for “doing harm.”
Well, I think that is a possibility yes, there is no stopping us. As health professionals we have to be very mindful of our ethical and moral obligations to patients. Part of it is, we do no harm. If something is doing harm it is not for the good of the person. Perhaps we are at a point where we are doing harm to people.

RN Lea’s philosophy was similar.

I guess my philosophy of it all is that anything we use is used in the best of intentions for the good of all. Sometimes it doesn’t come out like that but I think in the whole we try to do no harm and benefit the person. I think that is why we do the things that we do. I know of one individual who probably would answer yes, if he felt that he was being done harm. Unfortunately he has since died! But he was very traumatised about the whole thing for a very long time … and felt that he had really lessened his quality of life.

Both cardiac nurses Rae and Lea raised the fundamental concept of ‘first do no harm.’

In our modern world biotechnology is everywhere, in our history, our culture, and our daily lived-world. In health care society’s expectation is that biotechnology is available to prolong life. However, extending life by treating dying as a symptom (Dickerson, 2002b) rather than an existential event, as is the case with heart implantation with an ICD, can lead to “harm,” trauma, decreased “quality of life,” and inevitable death. For example, the combination of technological and human mishap, titled A Deadly Mistake, which claimed the life of a child during a ‘routine’ procedure, was witnessed by tens of millions of viewers on a televised program Dateline (Curran, 2002). Thus, the ultimate emotional dilemma is whether biotechnology such as heart implantation, has already reached “a point where we are doing harm to people.” The human price to be paid for extending life with an ICD emanates from lived-through-experience over time and space.

**IMPLANTATION AS BODY-SPATIO-TEMPORALITY**

Larry Dossey (1982, p. 143) described the body in a liminal context of space and time.

Bodies do not stay put; they are alive in space and time. The boundary of our physical self, our skin, is an illusion. It is no boundary at all, being constantly regenerated in only a matter of days. This ‘boundary,’ which feels solid to touch, is constantly fading, reforming, and fading again in the endless round of bio-dance.
RN Jody’s poem Fire and Ice was inspired by her experience of nursing a terminally ill man whose heart and body was implanted with a permanent ICD. The biotechnology that had extended his life in space and time became a liminal boundary, preventing him from crossing the ultimate boundary of death even in the “fading” of his body to cancer.

We were told it [ICD] was there. I heard commented that it would make it harder for him to die. He was in terrible pain. Probably would have been better if it was not there to help him live. He was in excruciating pain every time you touched him. It [ICD] wasn’t the focus of his care. You were lucky to have it mentioned at handover. It was not discussed. The only time I heard it mentioned was in comments in a negative light. His body was not able to give up naturally. It was a dreadful way to die. It [ICD] eliminated an option for him. He was just dreadful to watch.

Jody’s dialogue sinks the concept of time in relation to the permanency of the ICD to indescribable depths. In this instance, and I too have nursed patients in similar circumstances, the bioelectronic ICD is virtually ‘alive’ and functioning as it was designed to perform in body-space. Yet, in the same instance, a person was subjected to “terrible pain,” and “excruciating pain.” Permanency prevented a person’s time “to die,” “to give up naturally,” and “eliminated an option” to die a humane death. Humane nursing care and medical technology is irreconcilable when a person is dehumanised, alienated, (Barnard & Sandelowski, 2001) and deprived of dignity in death, because of controlled body-space and controlled dying-time. Physiologist Roy expressed his perspective on permanency.

I’d imagine some people would have trouble coming to terms with that and that they don’t have an option. And if they don’t like … the doctors just can’t whip it [ICD] out. OK, that’s fine, good, I don’t mind taking it out. Once it is in, it is in, essentially. I guess the fact that it is a life saving device it needs to be permanent. And I can understand some people having trouble coming to terms with the fact they have this device in there [the body] for the rest of their lives, yes.

Permanency means ‘remaining to the end’ and originates from the Medieval Latin permanentia (Pearsall & Hanks, 2001). As a health professional Roy’s perspective would significantly influence how patients viewed their body-space and lived-time. As Jody pointed out earlier “options” in body-space and lived-time were “essentially eliminated.” How does a person “come to terms” with such a permanent life-sentence? Implantation of heart-space and body-space, remaining to the end of lived-time casts the ICD as a two-edged sword that redefines life while redefining death (Dickerson, 2002b). Merleau-Ponty (1962, p. 364) wrote of this situation; “although I do not manage to
encompass my death in thought, I nevertheless live in an atmosphere of death in general, and there is a kind of essence of death always on the horizon of my thinking.” However, the paradox remains that while Roy and other health professionals advocate ICD technology as “life saving,” the only permanent survivor, “remaining to the end,” is the ICD. This is so because the ICD is removed before cremation of a person’s body (Anderson, 2000). Roy commented on this paradox; “Yeah, interesting concept isn’t it? Yeah, I think once a device is inserted people tend to take on a different identity. I don’t know if a person with deep significant religious beliefs, whether it would have an impact on them. It can become an issue.” Nevertheless, patients wanting explantation of the ICD confronted some cardiac nurses in this study.

**Being confronted with explantation of body-space**

Implantation of a person’s heart and body has been revealed in many different existential modalities over the preceding chapters. However, for some patients the motivation to include such a life-altering device as the ICD was not as strong as the desire to be free from a perceived bondage. I repeat Heidegger (1977, p. 4) who was aware of the potential bondage that technology is capable of commanding. “Everywhere we remain unfree and chained to technology. (...) We are delivered over to it in the worst possible way when we regard it as something neutral; for this conception of it makes us utterly blind to the essence of technology.”

RN Adel expressed a concept that offered insight as to why some patients requested explantation of the ICD from their body-space and lived-time. “They have said the shock from the ICD was like standing in the road and being hit by a Mack truck from behind. It is amazing patients are describing a life saving device with metaphors that in real life are capable of killing you. *A Mack truck would definitely kill you.*” Adel spoke of patients she observed as having “lost themselves.” Two patients impacted upon Adel; “They were like … ghost-like. I know it sounds like a funny thing to say but that was just the image I got. They were both incredibly withdrawn. They seemed to be here, yet not here.” In relation to body-space and lived-time these patients at some point in time “they had lost life.” As dialogue continued Adel spoke of explantation; “We had patients who came in who were so distressed with the shocks that they asked
for it [ICD] to be removed. Of course, well, we just did. I just thought that was quite amazing. The next lethal arrhythmia, they are going to die.”

Larry Dossey (1982) was open to the non-objective phenomenon of patients who defy the medical euphemism of ‘the natural course of an illness,’ patients whose cancer goes into remission against the odds and patients who die despite the odds in their favour. However, poet Clare McHarris’ (2003) work titled A Time To Die, held more hermeneutic appeal. The poem expresses adult memories of the childhood home revisited. The garden is overgrown, the windows are broken, and the sounds of childhood laughter and happy family times are no more. The final verse adds meaning for a person choosing explantation of body-space and thus a time-to-die.

I remember it now and weep for it all
And vision the Christmas tree proud in the hall
For the love of a house in its heart it does lie
And like all living things has it’s own time to die.

A time to die was further explicated by RN Rae who advocated for a lady who “decided not to do it. I think I have had a good life and why don’t we let nature take its course. She is still going at the moment.”

RN Fay expressed her perspective in relation to patients receiving multiple shocks.

It is not worth it. Um, once again that gets down to choice. Um, and then that would become very hard. I can certainly see that becoming very hard for everybody concerned because if they do take it out they are giving themselves a virtual death sentence. I think that would require a lot of counselling, and for everybody concerned. Oh, for sure. We have seen it happen. Yeah, but to be walking down the street, and to be kicked in the chest, or to wake up flat on your back on the pavement, it would be a horrible thing wouldn’t it? And you can see how the people would become extremely isolated. And that is not fair. I think none of it is fair, really.

Fay recognised the existential difficulty involved in a person’s decision to undergo explantation of the ICD from body-space. “Giving themselves a virtual death sentence” is what Larry Dossey (1982) referred to as annulling lived-time. Reference to “a horrible thing,” analogous to betrayal, is engaging in a taken-for-granted motility, such as “walking down the street,” and feeling the assault of kicking or the consciousness of being prostrate on the pavement. In terms of body-space, being vertical is a symbol of
life while being horizontal is a symbol of death (Grunbaum, 1973). The ICD that health professionals call life saving has the potential to do horrible things in space and time that are “extremely” isolating and unfair. Thus, implantation of body-space during such time-periods trigger denigrating evaluations (Inchaurralde, 1997), such as “it [ICD] is not worth it.” Similar to explantation was deactivating the ICD-effect in body-space.

RN Amy also used the descriptor “horrible” when recounting her experience with patients who requested cessation of ICD therapy.

I have seen doctors have to take it [ICD] out because they [patients] would rather die of a VT than have another shock. That is pretty horrifying. And there have been incidences of where we have turned it off. It is just too horrible for the patient. They can’t live like that. This one lady, she just hated it so much and every time she had a shock she would be in [hospital] and even though we would reassure her it was working perfectly, she really could not cope. She hated it so much that the doctors turned it off. Then she died. Even though she had all the psych counselling and stuff and her Mum trying to get her to save her life, she just pleaded. She hated being defibrillated so much. It was terrifying. She turned into a hermit and she couldn’t go out of the house. She lost her confidence and was worried about being shocked. They turned it off and the next lot of VT, she died.

Psychologist Rick agreed that lived-situations can be intractable and his dialogue reiterated the concept of life being impossible to “live like that.”

We had one guy here who had it go off hundreds of times and he just, he was in a dreadful state because he was, again, this thing [ICD], unpredictable, uncontrollable and whammed you with 30 joules of energy, over and over again. You couldn’t predict it. It wasn’t like, you could say, oh yes, 10 o’clock, time to get zapped. Of course, he was just so depressed and miserable. In fact, eventually, fortunately, it [ICD] got taken out. He couldn’t live like that.

A person’s body-space has as many different associations and meanings as there are beings-in-the-world (Merleau-Ponty, 1962). When people read of electric shock applied to body-space in the lived-time and context of torture, the associative reaction is spontaneous recoil from the horror and terror (Van der Kolk, 1996). Cardiac nurses and others can offer reassurance but remain in the liminal-space between empathy and living through the patient’s defibrillation. Body-space is sacrosanct to most people and it may be this very sanctity of body-space, self-space, ontological-space that patients perceive as lost when ICD defibrillation is “so much.” ‘So much’ of lived-time is referred to three times in Amy’s dialogue above. The association and significance of implantation, explantation, and deactivation, confronting cardiac nurses and patients, is body-space
and lived-time so complex that “we still have to become aware of it.” Merleau-Ponty (1962, p. 258) explained; “To experience a structure is not to receive it into oneself passively: it is to live it, to take it up, assume it and discover its immanent significance.” Yet, there can be no accounting for differences in human reaction. RN Guy told of one patient who [at that time] had not requested intervention; “Like he would get a fifteen minute break before it [ICD] would go off again and again. So he had that really horrific experience. That had been happening for a long period of time for him.” In contrast, “I have known of another lady who received the therapy [defibrillation]. I think she only received one therapy and she requested that the device be turned off.” Cardiac nurses in this study perceived empathic-time spent with patients was confined in the liminal-space of limited-time.

**Being confined in limited-time**

There was empathic distress for most cardiac nurses because of the restriction of time allocated to traumatised patients. RN Sue expressed frustration at the limited-time allocated to empathic interaction with patients scheduled for heart implantation with a permanent ICD.

> Not enough [time], basically, not enough. Because what happens is once the ICD is in, they are out of hospital. It is very frustrating. ICDs [patients] can be gone in a day, two days later. There is so limited time, and much less than I thought there would be. I suppose I feel frustrated. I feel that you can’t necessarily provide everything that you want to provide because of the limited time.

Merleau-Ponty (1962, p. 354) captured how cardiac nurses would contemplate the limitations placed on their empathic-time, even after the patient was discharged. “It is only retrospectively, when I have withdrawn from the dialogue and recalling it that I am able to reintegrate it into my life and make of it an episode in my private history, and that the other recedes into his/her absence, or in so far as he/she remains present for me, is felt as a threat.” RN Amy was aware of the “threat” that confronted cardiac nurses in the absence of preparation-time. “You don’t have the time and you can’t tell somebody what it is going to be like to have joules going off in their chest. Well, we can’t really prepare them for it. There is no way to prepare them for something that they have had no experience of in the past.” Amy refers to clock-time and temporality in her dialogue. The amount of clock-time necessary to prepare a patient for heart implantation with a
permanent ICD would be impossible to predict given the uniqueness of each person’s situation. In temporal terms, the absence of “past experience” with cardiac illness and ICD technology inflicts a complexity on limited-time that places empathic-stress on cardiac nurses. RN Rolf also spoke of time-limitation. “Given the [time] limits of working in a highly technical area, we will go all out to make sure that they [patients] are looked after in all aspects, including their heart, to having partners with them at all times, their children, things like that.” Rolf’s dialogue suggests that the “highly technical area” of cardiology is an infringement on empathic-time cardiac nurses can offer patients. Hence, the compromise of utilising family “at all times.” Yet, both patients and family need holistic-time from cardiac nurses. The patients’ ubiquitous situation of ‘waiting to know’ while cardiac nurses’ time is divided with technical things causes empathic-guilt to care givers (Hoffman, 2000).

Rolf’s other time comment “we go all out,” indicates cardiac nursing as a monochromic culture dictated and controlled by tasks and timeframes. Edward Hall (1989, p. 34) conceptualised task-time as “existing outside the individual with dehumanising effects as the external order of the clock is enforced at the cost of blindness to the humanity of its members.”

RN Gay noted a timeframe within which cardiac nurses can offer information, education, counselling, and support to a person scheduled for heart implantation with an ICD. “We have [patient] here on a Monday, we implant on a Tuesday, and they go home on a Wednesday. You have to be damn good at what you are doing. I just think it is out of my control. I can be angry but I know I can’t control it. I am angry that it has been allowed to degenerate to this stage.” The temporal context of day-to-day time activity relegates heart implantation to a sequence of beginning, middle, and the end. Gay expresses empathic-anger in two contexts (Hoffman, 2000). First, there is empathic-anger because cardiac nurses are limited and controlled both by nursing culture and the dictates of medical culture. Second, there is empathic-anger on behalf of the patients who experience waiting-to-know (Locsin & Matua, 2002).

Other cardiac nurses stipulated time-limitations that were considered acceptable. RN Kay explained. “We have good educational videos here for having an ICD put in. One to one time with nursing staff would be about 10-15 minutes. I find it is enough. There
are patients who you can tell are a little bit more anxious, so you spend a bit more time with them. Yeah. It doesn’t seem long. We are limited to time.” Yet, within the same dialogue Kay expressed, “In the last couple of months we have probably had two cancellations. The patients were just absolutely petrified.” It is not surprising that ‘time’ is the most widely used noun in the English language (Adam, 1995). Furthermore, when considering empathic-time it surely is not acceptable to lose sight of human complexity that bears no comparison to standardised time, which is “limited.” RN Guy expressed empathic-discomfort in relation to time-pressure.

Actually our waiting lists for devices are shortened so that it is much quicker for people to have an ICD inserted now. So I think that length of time to spend deciding about having an ICD, or even spend more time becoming more comfortable with having an ICD, has become shortened. We are becoming more efficient. That impacts on the individual. They don’t have as long to become comfortable with it, or even to decide about having it. The pressure is on I suppose.

Time is central to all human behaviour and interaction and is aptly described as the “silent partner in everything we do” (McGrath & Kelly, 1992, p. 399). In Guy’s dialogue the expression of time is paramount. For example, “waiting,” “quicker,” “length of time,” “to spend more time,” “shortened,” “as long to decide,” and “pressure.” The demands and pressures associated with ICD technology, operating theatre time, the dominant time of the cardiologist over nursing time, clock time, and most importantly the temporality of ‘now,’ all contribute to limited-time for cardiac nurses to engage with empathic-time. Just as space and time are part of the essence of existence, body-space and lived-time are part of the phenomenon of implantation of a person’s heart with a permanent ICD.

The other group of health professionals to be included in this study is cardiologists. As the health professional engages in heart implantation as part of their chosen specialty, it is imperative to this study to include their perspective.
CHAPTER SEVEN

INTERPRETING THEMATIC PERSPECTIVES IN CARDIOLOGISTS’ DIALOGUE

INTRODUCTION

Cardiologists are the fourth group of key players who participated in this study of heart implantation with a permanent implantable cardioverter defibrillator (ICD). The existential knowledge to be found in the dialogue of cardiologists in this study, demonstrates the persuasion that scientific knowledge can exert over a patient’s decision-making in relation to implantation. Cardiologists are the innovators, the initiators, and the group whose engagement in body-liminality, through the hybridisation of human-body and cybernetic-technology, can illuminate how and why The Liminal Body is possible. Through an understanding of the cardiologist’s existential perspective it may be possible for recipients of ICDs, family members, cardiac nurses and paramedical personnel, in this study, to confront The Liminal Body. Without this understanding there is the potential for a “turning point where I become conscious that I [self] can be annihilated” (Jaspers, 1986, p. 112) in the experience of implantation.

Cardiologists’ engagement in body-liminality through implantation of a person’s heart with a permanent bioelectronic ICD may be described as Kierkegaard’s (1968, p. 305) “leap of faith.” In this study, cardiologists’ leap of faith epitomises their existential challenge to extend life while potentially extending death, the ultimate liminality. Cardiology has a cultural history of engagement in body-liminality-states in that “life must be lived forward, but understood backwards.” This historical flow began with resuscitation and external defibrillation. Attempts have been made to minimise cardiac-related symptoms with medication technology. These leaps of faith are intended to reverse cardiac death from within the hospital setting and to extend life-within-the-world by implantation with the bioelectronic ICD. This history is detailed in Chapter two.
From the era of bioelectronics, including pacemakers and ICDs, cardiology has engaged in a new paradigm of heart-related illness. Cardiac-related illnesses are an unacceptable peculiarity to be managed by the intractable systems of biomedicine and bio-power (Foucault, 1976). In this way a person’s responsibility for his/her life trajectory falls under the agency of cardiology. Thus, as cardiologist Sean concluded:

We might find all these wonderful things and suggest all these odd and Frankensteinian type procedures and devices and so on. But unless we find out exactly what is important to the patient, we might be barking up the wrong tree. We might be doing something that the patient really does not want, or does not understand. And that is doomed to failure at some stage.

Table Four follows the thematic framework for this study and modalities are presented as emerging from cardiologists’ dialogue. As the most comprehensive dialogue, verbatim excerpts from cardiologist Sean are prominent in this chapter.

**Thematic Concepts: Table Four**

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**IMPLANTATION AS BODY-SEXUALITY/GENDER**

Cardiology is a male dominated specialty with approximately forty women (6.5%) cardiologists practicing in Australia (Australian Health Ministers Advisory Council, 1999). The female cardiologists contacted for this study remained silent, as did all but a few male cardiologists. Ironically, this meant that silence emerged as a commonality in this existential theme regardless of gender. However, in any minority group it can be found that silence is a technology that perpetuates the powerlessness of the few (Foucault, 1976). Thus, I can offer no contrast in opposite gender perspective for this group.
It is worthy to note the communication of cardiologists who declined the opportunity to be participants in this study. Two cardiologists were not in favour of the research question and put forward the perspective that it is not a person’s heart that is implanted with a permanent ICD. Both stipulated that in the phenomenon of implantation it is the bioelectronic ICD that is implanted. This perspective is a fair assumption when focus is channelled toward the bioelectronic ICD. Conversely, other cardiologists, with a more humanistic understanding, perceived no difficulty with the research question. One cardiologist communicated a patronising and paternalistic attitude; “I don’t agree with the research question but if you get desperate I will see you.” A further cardiologist, who initially agreed to dialogue, used up sufficient time to participate in the study with reasons why he was “too busy.” As a female cardiac nurse and researcher entering into dialogue with male cardiologists I experienced only one interaction of gender-tension. The participant continually attempted control by cutting into and anticipating questions. This technique can be distracting but I also found it gave me access to difficult areas, such as “responsibility and accountability.” Unfortunately, an emergency brought our lively dialogue to an abrupt closure. The same-gender male cardiologists in this study had similar technological perspectives on cardiology that led each one into this specialist field of practice.

**Being fascinated by cardiac technology**

In Western society, being technologically minded is viewed as a predominantly masculine attribute, possibly accounting for the small number of female cardiologists already cited. However, in this study, there is only the male-gender perspective of cardiologists represented.

Cardiologist Sean’s interest in cardiac implantation technology developed from the area of electrophysiology studies (EPS) and cardiac ablation:

> Years ago now I developed an interest in cardiac arrhythmia, and was most impressed by the capacity to successfully cure a number of arrhythmias with catheter treatment. That led me to pursue an overseas fellowship and in concert with that, the other half of the fellowship was basically ICDs.
This technological approach to the cure paradigm of medical science has been described as ‘boundary work’ that claims scientific territory (Faulkner, 1997, p. 187). Boundary work in medical science has a liminal no-man’s-land aura that is felt when viewing The Liminal Body.

Cardiologist Beau’s perspective was similar yet different; “It [cardiology] contained a good mix of both medicine and surgery and the surgery was technically demanding and satisfying. It is fine [intricate] work. The coronary is delicate.” Edge-of-life [liminal] technology (Tassano, 1995), such as implantation of a person’s heart, is claimed to be a routine procedure. Yet, Beau became interested in cardiology because he perceived the specialty as “technically demanding” and “delicate.” Thus, edge-of-life technology, such as implantation, was fascinating because of the challenge engendered by delicate manipulation required in hybridisation of a person’s heart.

Cardiologist Zane was more mechanistic in his perspective; “I have always considered the heart as a very complex human organ although it only is a muscle. The variety of heart disorders from electricity to mechanics caught my interest early.” Zane, as well as Beau, was challenged by the complexity of the human heart. However, Zane’s challenge was more the cause and effect or aetiology of the contemporary concept of the Untamed Heart (Bill, 1993). Untamed Heart is a contemporary film of a young man with congenital heart failure.

Merleau-Ponty (1962, p. 22) wrote of the mechanistic perspective; “The physicist’s atoms will always appear more real than the historical and qualitative face of the world, the physico-chemical processes more real than the organic forms.” Cardiologist Gary was evasive about his engagement in cardiology.

Well, it is not … I don’t know that it is very common. It is something to do (laugh). We all have to do something with our lives. [More personal?] No. I mean I enjoy doing it. But I could have equally enjoyed being a chest specialist or gastroenterologist or neuro-surgery. No special attachment to the heart.

In dialogue with some health professionals in this study it was inevitable and unavoidable that the subject of moral stance and ethics would be raised. Physician and writer Sherwin Nuland (1995) suspects, in comparing the Greek Hippocratic physicians of medical history with contemporary physicians, in everyday ethical medical science
there is neither more nor less success in practicing moral behaviour. Cardiologist and ethicist Neil presented a broad, humanistic perspective for working in the field of cardiology and ICDs:

Heart diseases affect many people. I prefer to work with diseases that are not trivial. The speciality involves both acute and palliative aspects of care. Moreover, one is faced with several intellectual and ethical challenges when working in the field of cardiology.

Once again the concept of challenge featured significantly in a cardiologist’s perspective. The challenge for Neil appeared to rise from multiple fronts, including the affect on “many people,” the life-threatening potentiality of the untamed heart that cannot be trivialised, the edge-of-life/death palliative care of heart failure, the intellectualism of diagnosis and treatment, and the ethically challenging dilemmas of decision making.

In contrast, cardiologist and ethicist Rhys reflected on the technological excitement and amazement that “the beginning” of cardiac pacing inspired in many medical scientists; “From the beginning it was because of the acute cardiology and the amazing development that occurred in the end of the sixties and the beginning of the seventies.”

There is always the intention with new technological developments that the innovation will result in a cure for life-threatening illness (Cassell, 1997). Failing a cure, the hope is for life-extension with a minimum of complications. As Rhys later indicated, this was not always the outcome in relation to implantation of a person’s heart with a permanent ICD. Merleau-Ponty (1962, p. 17) wrote of expectations; “I merely felt that the look of the object was on the point of altering, that something was imminent in this tension, as a storm is imminent in storm clouds. Suddenly the sight before me was recast in a manner satisfying to my vague expectation.” Thus, with the ICD’s capability to alter the heart and to hybridise the person’s identity, how does the cardiologist engage in the challenge of implantation as body-liminality?

**IMPLANTATION AS ENGAGEMENT IN BODY-LIMALITY**

Body-liminality in a life-threatening illness has been described as a “black box” (Little et al, 1998) where a person is set apart from others in the disturbing boundedness of
life-and-death (Giddens, 1990). Sustained body-liminality resembles black holes of experience (Hawking, 1988) where survivors of life-threatening illness, such as a sudden cardiac death episode, are confined in an oscillating life-and-death vernacular between body and self. Cardiologist Gary used the phrase, “change in body-habitus.” This use of the vernacular by the cardiologist shows his body-self engagement in body-liminality through the implantation of a person’s heart with a permanent ICD. Cardiologist Sean added meaning in the way that his perspective involved people.

I think there is always something more to learn about people’s hearts, and I think one of the things that interests me is how people’s attitudes and opinions actually influence what happens to their heart’s physiology. I think that is one of the major challenges in cardiology … is to integrate the psychological and physical aspects of cardiac function.

**Being-in-the-world of engagement in implantation**

Professor of Medicine, Psychiatry, and Medical Humanities, Timothy Quill (2001) argues it is an unduly simplistic notion that patients have autonomy in life-threatening situations, such as heart implantation. Cardiologists offer information, present options, relay statistically relevant risks and benefits, and make recommendations in relation to the highly technical ICD. The life-threatening event or the recommendation, whichever happens first, is the beginning of body-liminality. Cardiologist Sean explained, “you have to make it [implantation] simple enough so that they do understand.” He continued with how he would offer implantation information.

You go onto what the positive aspects are. What the chances of success are. What the chances of failure are and tell the patients what they are. And then say, is that what you want? Here are the options. You can do nothing and carry on as you are, right, with these risks. You can have drug therapy, which most of them are already taking … forever. These are the pluses and minuses of that. Or you can have this procedure and have this device. They are the options.

The dichotomies of implantation outlined by Sean are far from simple; positive opposed to negative, success opposed to failure, risks opposed to benefits, pluses opposed to minuses, medication opposed to the ICD. Similarly, cardiologist and ethicist Neil spoke of dichotomies:

One must of course follow the medical development and at least have some basic knowledge of ICDs. It is therefore important to know when ICD therapy might be indicated and to understand the possible advantages and disadvantages associated with it.
Body-liminality is spiked with dichotomies because heart implantation continues as a life and death threshold.

Patient decision-making as a passive role has been equated with physician paternalism that controls and dominates the patient’s options (Quill & Brody, 1996). The question of whether the cardiologist’s knowledge and power presented a barrier within engagement in implantation prompted the following response from cardiologist Gary.

I don’t think so. Patients come for help. I mean I tell them what I can do and I … they make the decision. I make the recommendation but they choose to go ahead. I don’t say, like, you need it [ICD]. I say, like, this is what your life is going to be like with it [ICD]. If you want to go ahead … fine. I make the recommendation … they choose. I don’t choose for them. I don’t insist they have anything. So it is their choice.

While Gary rejected the notion of personal barriers between patients and cardiologists, Timothy Quill (2001) experienced difficulty with a patient who refused invasive technological treatment from the perspective that the physician was not the person living the treatment. Similarly, cardiologist Sean responded to this notion.

You mean because I have not been there myself? Um, I think there are barriers between everyone in any situation. And that is why all the cards have to be put on the table. Patients often say to me, “What would you do?” And I say, “Well, that is not a fair question because this is not me, this is your life and I am here to give you advice. I am not here to live your life for you.” That takes a bit of getting round sometimes.

The ways of engagement in heart-implantation, as in any life-threatening state of body-liminality, are multifaceted and complex. Timothy Quill (2001) strongly recommended technology-dominated approaches to patients in life-threatening situations. He also recognised other engagements, such as paternalism and control. Conversely, the too-passive physician alienates patients in body-liminality through the absence of a negotiating partnership. Sharon Kaufman (1997, p. 191) wrote of the “most laissez-faire approach” as being within the statement, “It’s his [her] decision. It’s your job to inform him [her] of the options.” However, Sean added, “It is very hard to give them [patients] information in a neutral way, because we are all enthusiastic for new technology and um, we think we know what we are doing” (sardonic laugh).

Cardiologist Beau used the descriptor “borderline,” which definitively locates engagement in body-liminality for all involved in life-threatening cardiac implantation.
You realise that what you are doing does have … no matter what you do somebody is going to die. You are never going to get through a year, ah, a year without somebody dying. You are going to operate on people, you are going to choose people who are borderline: whether you should be doing them or not. You give them a chance and you tell them that. You know this is a chance, and you may not make it through.

Beau relegated cardiac survival to a life-death-liminality described by H. Evans (1993, p. 83) as an “ever-widening chasm” of technological body-hybridisation. The concept of “chance” in relation to medical science yielded more than six hundred articles from the ProQuest database. Engagement in chance by cardiologists would place enormous stress on a person already close to ultimate body-liminality. Laura Landro (2003, p. 2) cautioned about “too much responsibility on patients for safety, because it may end up shifting blame for error to the victim.” In contrast to Beau’s perspective, cardiologist and ethicist Rhys’s perspective on heart implantation included engagement in the least amount of chance; “I am still very much in doubt if this [implantation] is the right way to treat people in most cases. But, for some, where the diagnosis is absolutely correct and there is scientific evidence for a successful outcome, I recommend it.”

Undoubtedly the quantitative epistemology of medical science (Gallagher & Durant, 1993) that aims for “correct” diagnosis, “scientific evidence,” and a “successful outcome,” is invaluable in decreasing physiological chance. However, as cardiologist and ethicist Neil argued, this epistemology can be coupled with patient wellbeing.

The physician is confronted with several medical and ethical questions when deciding whether or not a patient should be offered an ICD. Does the patient have a sufficiently high risk of a sudden cardiac arrest, which can motivate an ICD? How will the therapy influence the patient’s physical and psychological wellbeing? In fact, generally speaking I am neither particularly interested in nor good at high technology devices/medicine. I consider myself being more of a generalist, or perhaps humanist, than a ‘sub-specialist.’

Similar to Rhys, Neil’s concern related to the efficacy of heart implantation with an ICD as indulging in “high technology devices” that hybridise a person’s body and alter his/her “physical and psychological wellbeing.” This engagement in an altering potentiality is what I have argued in this thesis to be implantation as body-liminality. Neil’s perspective is tempered with a humanistic empathy for a person’s wellbeing that relegates the bioelectronic ICD to a secondary consideration. Professor of Psychology, Martin Hoffman (2000, p. ii), considered such a perspective as “empathy’s contribution
to altruism and compassion for others in physical, psychological, or economic distress.” Nonetheless, ICD technology does have its advocates. Cardiologist Zane viewed the ICD as the “solution:”

> We cardiologists thought for many years that pills would save these patient’s lives. They didn’t. The solution was a device that could work for outpatients. Not many other treatments have so direct an impact on life and death as an ICD. It is thrilling to handle such a treatment.

Returning to the concept of efficacy in relation to ICDs, Warren Strugatch (2002, p. 6) emphasised the point that high-power technology is considered “synonymous with efficacy” by cardiologists. Furthermore, cardiologists were portrayed as more committed to advancing invasive technology, such as laser surgery and “implantation,” because this technology has been touted extensively in professional journals and seminars. This argument by Strugatch (2002) would thus partly explain why it was a struggle to get cardiologists’ attention when challenging the efficacy of unquestioning engagement in implantation of a person’s heart as body-liminality.

As already stated cardiologist Sean was asked by potential recipients of ICDs, “What would you do?” Sean thought this an “unfair question.” However, during dialogue I asked, “Would you have an ICD?” Sean’s response held reservations.

> I think it would depend on the circumstance. You know, if I had an event, if I was in a situation, which was um, … consistent with current medical practice and evidence, then I will do it. Um, I don’t know if you watch Star Trek, but Spock says, there are always alternatives, captain! (laugh) … you know? And so you put the alternatives. You say well, if we do nothing then your risk of death is X% in 2-3 years. And with the device it is a bit less. It might give you 5 years or something like that. And some of them say, well, I will take it. And they are allowed to change their mind later on.

Sean’s dialogue encompasses the liminality-effect. He related to acceptance of the ICD in the first person “I” while considering the “circumstance” of a cardiac “event,” and while engaging in the cardiologist’s comfort zone of construing the body in terms of “current medical practice and evidence.” However, a reference to the hybridised and unemotional Spock from a popular science fiction television program, Star Trek, provided relief from delving into his first person issue of mortality. Thus, the ultimate liminality of life and death risk is dissociated in the context of second person “you,” and third person, “them.” Death, as the ultimate liminality is given the unknown quantitative value of “X%.”

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The ontological question of whether cardiologist Gary would accept implantation of his heart with a permanent ICD sparked a philosophical debate. His final response was initially dissociative yet with a different persona to Sean.

I don’t know if I can help you. I guess … (fumbled with study sheets). Well, if you want to know what patients feel about it, you have to ask them. If I needed one [ICD] I don’t know what I would feel … until I needed one. I mean it is something I don’t even think about. [Why?] Sure. Well, there is no point in crossing bridges until you come to them. I don’t go around thinking about problems. I guess I spend too much time dealing with them. Yeah. I don’t think about having one personally. There would be no question. If I had … if I was at risk of sudden cardiac arrest, I would have one.

The procrastination expressed by Gary suggests that there are cardiologists [and other practitioners] who become so engrossed in other people’s life and death liminality, and possibly the power and prestige that surrounds such mystique (Tassano, 1995), that a sense of untouchability evolves.

The concept of being untouchable because of power and prestige brings to mind the film titled, The Doctor (Ziskin, 1991). This film was based on the autobiography of physician Edward Rosenbaum, titled, A Taste of My Own Medicine. The title is self-effacing in that the film character is a cardiologist who has long treated patients as ‘other people,’ who have life-threatening illness, until he is diagnosed with throat cancer. Thereafter he becomes part of a long line of patients on the other side of body-liminality, lost in a mechanised health care system. As a patient, Edward Rosenbaum was forced to see the bureaucratic hospital image, physicians, and medical treatments, from a patient’s perspective. A technically competent physician disdainfully informed him of his diagnosis, which he was unable to assimilate. In the film, as in reality, Edward Rosenbaum initiated an educational program for medical students to instil empathy and humanism, insisting they be treated as patients for a time to experience directly the humiliations of modern medicine. The film has become required viewing in several medical schools as a lesson in humanitarian care (Clark, 2001, p.146). Hence, the perspective of “no point in crossing bridges” into body-liminality prevents the cardiologist from attaining a humanistic understanding of heart implantation with an ICD.
The meaning of implantation of the heart with a permanent ICD appeared, from cardiologist Beau’s dialogue, to revolve around physical symptoms. His response to the phenomenological question of personal implantation was initially strained.

Um … well, it would be for a life-threatening condition. I would accept it, very willing, very gratefully, very willingly. If I was given the opportunity, if I had a VF arrest or something like that. I mean it would save my life next time, so I wouldn’t have a problem with it at all. I mean there would be a comparative as to whether you were waiting for it to go off or not. But I mean what do you do without it? Do you wait for your heart to defibrillate and not survive? I don’t think there is really much … it is a difficult situation.

As a cardiologist, the thought of dying from a life-threatening illness when highly technical life-saving devices, such as the ICD, are available was not compatible with Beau’s worldview. Lacking clarity surrounding the goals of medical science and life-extension is not usually part of the medical dialogue (Quill, 2001). Furthermore, a lack of support for medical technological intervention could cast doubt on professional dedication. However, Beau questioned the “difficult situation” of choosing between life-extension and living in wait for the ICD “to go off or not.” Thus, engagement in implantation engenders body-liminality for cardiologists. The above dialogue begged the question of whether Beau considered his own mortality, “Oh. No. I mean it is like anybody thinking about their [his/her] mortality. I don’t really think about it. I mean, why worry about it? It is something I might have to face in the future, but I can’t do anything about it.” Cardiologist Zane supported the worldview discussed above; “I am positive. And it [ICD] supports my task as a doctor, but one must consider all its impact, not to forget quality of life.” In supporting the “task” of being a cardiologist who extends and prolongs life, it would be imperative to establish and maintain a body-relationality that patients viewed as benevolent.

IMPLANTATION AS BODY-RELATIONALITY

Timothy Quill (2001, p. 26) reflected on his team battling against death by using all available medical technology. These efforts to keep patients alive seemed “monolithic” and often futile. He described how his team would electrically shock the heart repeatedly, sometimes crushing the chest of patients in overzealous CPR, and technologically invading all parts of the body. He questioned the objectness of extreme
medical measures and wondered what affect these technologies had on patients’
subjectivity. Merleau-Ponty (1962, p. 350) would have agreed with Quill’s doubts:

But we have in fact learned to shed doubt upon objective thought, and have
made contact, on the higher side of scientific representations of the world and
the body, with an experience of the body and the world which these scientific
approaches do not successfully embrace.

In view of cardiologist Sean’s claim to a trusting body-relationality with patients, I
posed the question; “How did you assess their level of acceptance?” He replied
spontaneously.

Well, I ask them. You know, what do you think about this? Do you think it was
the right thing to do? What do you think this procedure is going to do for you?
What do you think this would mean for you? What do you think about not being
able to drive … possibly forever? You know, I have had a couple of them tell
me “I would rather be dead if I could not drive.” I don’t think they really mean
that, but they are just trying to get the point across that um, it is extremely
important to them. So it is a symbol of their independence and control.

While I asked Sean an epistemological question about how he knew patient’s level of
acceptance, he pursued patient’s ontological understanding of what personal meaning
they assigned to heart implantation with an ICD. A person’s body-relationality to the
prospect of losing previous nuances of personal meaning is fundamentally an unknown
(Cassell, 1997). Only the concrete “symbol of their independence and control” can be
assimilated. Being without personal independence and control means to some patients
that they “would rather be dead.” This personal meaning, having been raised by Sean,
then becomes part of his body-relationality as a cardiologist. Thus, Sean was
confronted with the nexus of heart implantation with an ICD. Sean responded.

I usually tell the patients something like, in the spectrum of patients you know,
in the range of patients who get these devices, there are some people who walk
around with them [ICD] who are absolutely terrified the whole time that it is
going to activate. There are other people at the other end, who have this little
life-saver in their chest and they go about their business confidently, knowing
that if they do have a problem, the device will fix it. It might be painful but it
will fix it. Now there is everyone in between. I try to get the patient to visualise
where they are on that scale and tell me. One end is confidence I guess, and
adjustment. The other end is diffidence and lack of adjustment.

It is within the cardiologist’s worldview to categorise a person’s perception of
body-relationality “in the spectrum” of self-image. In Sean’s worldview patients were
categorised as “absolutely terrified” and living “confidently.” The body-relationality
for a person with a life-threatening illness compounded by heart implantation can be a state of liminality where one end of the spectrum is a worldview-distance from “the other end.” The loss of independence, control, and self-perception is understandably more traumatic for some patients than for others. Thus, Virginia Woolf’s (1929, p. 17) perception of this trauma is insightful; “The beauty of the world has two edges, one of laughter, one of anguish, cutting the heart asunder.”

In body-relationality with patients cardiologist Gary used the concept of “coming to terms” rather than adjustment or confidence.

There are some people who have trouble coming to terms with the device but as I said they are the young people who don’t want a device because they don’t want to think that they need anything to maintain their existence. Ah, but once they come to terms with that … particularly if they wait until they have a second episode where they pass out, there is no question then, they are in here the next morning.

As a cardiologist engaging in life and death cardiac situations Gary’s persona failed to communicate [to me] an empathic body-relationality. While his dialogue demonstrated he was aware that patients experience existential threat represented by the ICD device, Gary appeared self-satisfied in that “there is no question” patients would eventually “come to terms” with his diagnosis and recommendation for heart implantation. My query as to what this meant to a patient’s quality of life was cut short, “Well, not too good at the time. I mean, if he did not have the defibrillator there, I know what that would do to his quality of life. He wouldn’t have a life.”

Coming to terms with life-threatening body-relationality is a complex human dilemma because people attempt to hold fast to their previous self-relationality. Life-threatening illness becomes a liminal-relationality; it is a phantom-self (Athens, 1994). Athens (1994) discussed phantom-self within the context of altered-self. Body-relationality to implantation disembodies the future-self as altered and hybridised, there is the loss of an irretrievable past-self. Irretrievable past-self emanates from the liminal-relationality of altered-self. Loss, change, and life-threatening liminality states, results in a singular self becoming a phantom-community; there is a “new phantom community comprised of at the minimum, some phantom companions [selves] who are different from those of the former phantom community [selves]” (Athens, 1995, p. 575). Thus, coming to terms with body-relationality perceived as phantom-self extends to all people,
cardiologists and truck-drivers alike. Within the nature of implantation, the loss of multiple selves, such as the mentioned professions, evoked reflection.

Cardiologist Beau reflected on continuing his profession in the event he needed an ICD.

Oh, I don’t think so. It [ICD] might go off during the procedure. I would give up my job. I don’t know. I have not faced it. I have not had to face it. But that is with a lot of conditions too; if I lose the function of my hands; if I had a stroke. But you can’t and don’t think about that.

Cardiologist Gary chose to reflect only on the truck-driver; “Without the device he would have to give that up. No chance without the device. Absolutely. With the device, his career has gone anyway.”

The concept of “absolute” was a significant feature of Gary’s ontology within the essence of implantation. Similarly, yet within differing contexts, “absolute” entered into the ontology of cardiologist and ethicist Rhys. Rhys expressed “belief” and “firm opinion” where “the diagnosis is absolutely correct.” Absolute, in philosophical application is that which exists without being dependent on anything else, ultimate reality (Pearsall & Hanks, 2001). In addition, absolute originates from the Latin absolutus, meaning freed, unrestricted. Thus, the unrestricted power and control of the ICD over life, death, and a person’s-place-in-the-world, sanctions the cardiologist’s chosen approach to body-relationality in heart implantation.

**Being in body-relationality to the ICD**

Throughout this study cardiologists and other health professionals have advocated that heart implantation with an ICD will “fix it;” the life and death struggle within a liminal body-state. However, not all recipients are as convinced of the ICD-efficacy as cardiologists. The cardiologist’s body-relationality to the ICD-efficacy is challenged when recipients question this efficacy (Lupton, 1995). Having to deal with this situation was viewed by cardiologist Sean as “a difficult problem;” “It is a difficult problem … it is a difficult problem.” I asked Sean, “How do you deal with that?” After some silence I probed further; “What would you say to me?” After some reflection Sean responded.
Well, first of all, let us work out that the shocks are appropriate, you know, that
*the thing* [ICD] is working properly. Assuming that it is, then, I just have to
point out again what the options are. And um, if the patient really did not want
to have it replaced, then I would not do it. But they have to know what the risks
are … next time they get this arrhythmia they will probably die. And they might
be happy with that. And that has happened.

Professor of Medicine, Jon Neher (1999), acknowledged how difficult it was for
physicians to have their technological and physiological worldview scrutinised by
unsure patients. This difficulty was evident in Sean’s dialogue where he labelled the
ICD as “the thing.” Cardiologist Beau was similarly discomposed when the question of
his body-relationality to implanting the heart with an ICD was posed.

Well, I don’t have any problem. I mean ah, I don’t have any problem with it at
all. I mean I don’t have any feeling. If a patient needs a pacemaker, paced
because of a life-threatening problem, and if a patient needs an ICD for a life-
threatening problem. That makes, I don’t know, it makes no difference to me. I
don’t think about it. Oh, I don’t know. The patient needs something to survive,
so they are going to get some device. That is the way it usually is. You don’t do
this if the patient doesn’t need it.

Professors of Medical Anthropology, Jeffrey Borkan and William Miller (1999),
compared worldviews of physicians, regardless of specialty, finding that physicians
enter the clinical encounter milieu with a mix of medical culture complications and
insights. Despite some uncertainty about body-relationality to patients, Beau appeared
committed to technological survival in the event of a “life-threatening problem.” In
contrast cardiologist Gary’s perspective was definite, even though as previously stated
personally, “it is something I don’t even think about.”

Well, I implant them [ICDs] all the time, so I have no trouble. I think they are
an excellent device. And they have saved many lives. So I am all for them
[ICDs]. These are patients with a life-threatening illness, so there is no doubting
in their mind that they need something done. They just survived a sudden
cardiac arrest, so they are quite accepting. They are happy that something can
be done. They are quite accepting that it is a simple device that is implanted.
Takes about an hour to implant. It is … there is no major haggling or gut
wrenching about it. They are happy to go forward.

Ironically, Gary’s descriptive phrases, “no major haggling or gut wrenching” are
comparative to phrases already reflected upon from very unhappy recipients in Chapter
four. Gary’s claim, “I have not had any patients like that,” was unconvincing even
though he also claimed, “I implant them [ICDs] all the time.” Gary’s persona as a
cardiologist brought to mind the account by physician Michael Klein (1999, p. 197)
whose wife suffered panic attacks while in ICU. Attending health professionals stated, “What’s her problem? We saved her life.” Michael Klein’s conclusion was fitting to Gary’s body-relationality. As a physician, Michael Klein was aware that there exists, for some physicians, a fear of failing to be perceived as omniscient. Moreover, it is more difficult when faced with a co-professional.

In contrast, cardiologist and ethicist Rhys’s body-relationality to heart implantation was balanced. Rhys offered his personal perspective, “I have no objections as I know that the pacemakers [ICDs] have been a great help for many patients.” However, his body-relationality in respect to his patients led him to balance his belief, “I believe that quite a few are sceptical. Some because they think that they will not die in a proper way and some because they have experienced that the ICD will give a shock. I am sure I would explant it or turn it off [if requested].” Dying “in a proper way” can be interpreted in a way “that one’s own body evades, even within science itself, the treatment to which it is intended to subject it” (Merleau-Ponty, 1962, p. 72). The subjective person wants to preserve body-dignity and serenity of spirit in the ultimate liminality of dying. Emily Dickinson’s poem titled, ‘Death is a dialogue between,’ adds meaning to body-dignity and the triumph of the human spirit in death (Dickinson, 1975, p. 456).

Death is a Dialogue between
The Spirit and the Dust.
"Dissolve" says Death - The Spirit "Sir
I have another Trust" -
Death doubts it - Argues from the Ground-
The Spirit turns away
Just laying off for evidence
An Overcoat of Clay.

Cardiologist and ethicist Neil echoes the above perspective albeit in different words. However, there appears to be reflective disappointment in Neil’s dialogue. His body-relationality with the technologically esteemed ICD and with patient’s “over-optimistic view,” reveals a worldview of acquired wisdom that goes beyond the cognitive and scientific paradigm to touch the human need to extend life albeit through hybridisation.
According to my experience patients who have ICDs do not think so much of their devices as one might have expected. The majority of them have a very pragmatic attitude. They rely on the judgement of their physicians who have recommended the therapy. The patients in general accept and feel confident with the device. However, I feel that many patients with ICDs have an over-optimistic view of what can be achieved by having a defibrillator implanted.

Neil’s perspective contrasted with cardiologist Gary’s perception of body-relationality to ICDs and patients:

I accept that there are people who are expressing different things. To me, they are obviously grateful for having put the device in and saving their life, but they don’t want to burden me with problems that they perceive with the device. I realise that happens.

Professor of Medicine Jack Medalie (1999, p. 49) acknowledged that physicians learn more from patients about healing, disease, living, and dying, than any textbook, journal, or scientific research. He believed that the physician’s perspective, feelings, attitudes, and personality, contributed undeniably to body-relationality whether it entailed highly sophisticated technology, such as ICDs, or patients whose illness “manifestations, if unusual, challenge dogma and can lead to reflection and change.” Thus, as Jack Medalie concluded, the physician’s body-relationality may be his/her strongest therapeutic agent. In this study group it was necessary to probe for emotionality in relation to heart implantation with a permanent ICD.

IMPLANTATION AS BODY-EMOTIONALITY

J.C. Fletcher, a medical ethicist and a ‘hearing’ son of deaf parents, narrated how his father became deaf at age four after a long period of medical treatment for an unknown illness (Nukaga & Cambrosio, 1997). However, the legendary account that spread throughout Fletcher’s farmland district was that his father survived a lightning strike, which resulted in his deafness. The story illustrates the liminal gap existing between the medical voices and the narrative voices of ordinary people (Atkinson, 1995). Thus, the medical pedigree is protected and removed from the body-emotionality of unsatisfactory outcomes. The subjectivity of body-emotionality is avoided or suppressed by many physicians in maintaining medical objectivity and personal assurance (Kleinman, 1988).
Merleau-Ponty (1962, p. 353) wrote of assurance; “The cogito of another person strips my own cogito of all value, and causes me to lose the assurance which I enjoyed in my solitude of having access to the only being conceivable for me, being, that is, as it is aimed at and constituted by me.” Cardiologist Gary suggested that I follow his worldview in the current study; “I think if you are going to do any ah, major study, the ah, best thing to do would be to get a patient list and to send them out some sort of short survey.” Gary valued epistemology over ontology; “The brain is where all the action is, from the point of view of thinking.” Similarly, cardiologist Beau thought the scientific worldview was possibly the way to deal with heart implantation; “Oh, I have no idea. That is the way I deal with it. That’s the way I learned. I’ve got no, ah, I mean, you can’t be thinking of other things [the patient], when you are doing the operation.”

Physician and poet Marc Straus writes about what he hears with his ‘inner ear’ from patients with life-threatening illness (Gelb, 2000). His writing expresses the perspective of patients who describe physicians as good clinicians who are technologically competent but who fail at empathic communication and human connection. Marc Straus perceives his poetry as a bridge to possibly span the liminal gap of body-emotionality between emotionally insulated physicians and patients with life-threatening illness. In this study of heart implantation it was unavoidable for cardiologists to acknowledge being-in-the-world of body-emotionality. Body-emotionality was expressed in dialogue, more for some cardiologists than for others. A number of cardiologists expressed their body-emotionality with difficulty. For example, cardiologist Beau experienced ambivalence in the expression of his body-emotionality avoidance:

Oh. I think the heart is … no, I think, I don’t think … I don’t attach any emotion to the heart at all. It is an organ there to function. What it does, it pumps blood around the body. It is an important organ, but I don’t consider it … I don’t put any emotion to it. I don’t think it is a soul, or anything like that. I know people do. I don’t.

It was interesting that Beau introduced the concept of “soul,” when it had not been previously mentioned in the dialogue. During further dialogue with Beau there appeared a degree of personal guilt; “Yeah. What we do is very mechanical. It is very hard to think that you are operating on a person and how important that is.”
Being-in-the-world of body-emotionality

Being responsible for others’ welfare is part of being a health professional. Body-emotionality as ‘responsibility guilt’ (Hoffman, 2000) is a likelihood for most empathic cardiologists when patient outcomes are less than expected. Cardiologist Sean was prepared to express how he dealt with “a sense of failure” when rejection of heart implantation with a permanent ICD led to a patient’s death.

Well, I was happy that the patient understood what it was all about. And sure, they do move along that continuum. You feel a sense of failure in a way of course. Well, we didn’t explain it properly in the beginning, didn’t point out all the possible contingencies. But then you think, well, I should not beat myself about the head for that because you couldn’t possibly predict everything. Um, then you think well, maybe there was something else we could have done. Or maybe there was some other kind of drug therapy that could have made life a bit easier for them. Once you have been over that, it is a matter of flicking the switch off.

Sean’s dialogue expresses the pendulum-effect of body-emotionality within feelings of guilt. Emotion and rationalisation interchange as feelings of body-emotionality are worked through. Despite the evidence outlined by Sean to the contrary, his cause of responsibility evoked feelings of being a “failure.” Conversely, Sean was initially “happy that the patient understood what it was all about.” Therefore, his dialogue may involve shaken personal assurance as outlined by Merleau-Ponty at the beginning of this theme. Perhaps, for Sean, there was knowledge to be gained from this situation that is more professional than emotional, although Beau admitted feeling that “it is still disappointing.”

Sean’s dialogue “you couldn’t possibly predict everything” brings to mind the closing lines of Marc Straus’s poem titled The Sigh, in which a patient reflects on her physicians’ body-emotionality; “He has no tolerance for remonstration, his head is so cluttered with obligatory data. I might articulate my pain but he is filled with dying and I’m obliged to keep the sigh inside” (Straus, 2000, p. 3). I probed as to how Sean dealt with the weight of responsibility and accountability. His response was a liminal dilemma of logic and moral emotionality.
I would say that the patient is going to die one day. They really are, like the rest of us, going to die one day. And it may not be the heart that kills them. And that brings up a whole lot of other issues like, this is something that has not been well documented in the literature. There are patients who live long enough to develop cancer. And that is a … that brings up a whole lot of other problems. I think it is one of the sleeping problems in cardiology, is that people are living longer with cardiac problems, and more of them are developing cancer. And I find that a bit difficult to deal with.

The logic in Sean’s dialogue is that no one can predict how another person will ultimately die. The moral emotionality is anticipatory guilt (Hoffman, 2000). Martin Hoffman defined anticipatory guilt as feeling guilty at the thought of causing harm or increasing the likelihood of harm, however unintentional. Such is the nature of extending life through heart implantation with a permanent ICD. The “sleeping problem in cardiology” arose during the course of this research. For example, a female recipient with a family history of breast cancer received the results of a breast ultrasound following lumpectomy. The results specified that the ultrasound was unable to assess breast tissue beneath the ICD. Such is the liminal nature of implantation.

In contrast to Sean, cardiologist Gary experienced difficulty with the concepts of responsibility and accountability in extending a person’s life through hybridisation. Gary included an interesting concept that I had not mentioned; “Does that absolve me of responsibility?” After unrelated dialogue, Gary responded to his own question.

I explain to them what the problems are going to be because everything in this world is not perfect. If they are unhappy, well, then the device can be pulled out. There is no problem with that. But I have not had any patients in ten years who wanted that to happen; who has wanted his device to be taken out. So that is a lot of people.

The meaning of ‘absolve’ is to be free from responsibility (Pearsall & Hanks, 2001). Gary appeared to equate being free from responsibility and accountability with the truism “everything in this world is not perfect.” I pursued the concept of imperfection for recipients whose quality of life was less than desired, such as being shocked to the ground in public by the ICD-effect. Gary’s response held defensive emotion.

Well, it depends on, you know … for people who know that if they don’t get that [shock], they will be dead. I like to think they would be dead. So for people who have experienced that [shock], that is more to the point. I have had patients going out to a restaurant, walked in the door, collapsed, rescued, and went on and had their meal. That is excellent therapy. I mean you [directed at the interviewer] have to get that message out.
In Gary’s dialogue the prospect of death is absolute vindication for heart implantation and for ICD bioelectronics. In describing a recipient’s experience of shock therapy in a restaurant, there is no expressed empathic concern for the body-emotionality of the person that has been extensively presented in past chapters of this study. Gary accepted that prevention of the death of a patient led to no doubting the “excellent therapy” of the ICD. Such dedication to implantation technology contrasted with physician Marc Straus (2000) who advocated after more than twenty-five years of dealing with patients in life-threatening illness, “I try my best to absorb some of their anxiety by working really hard to support them. You have to learn to hear your patients.” Gary responded to the question of patients who refuse ICDs.

There have been a number of cases of young people, who have said, no, I don’t want the device. It is their life. They have to accept that. But they accept the risk of going out there and living their life. I can’t determine when they are going to have the next cardiac arrest. It might be twenty years from now. It could be tomorrow. All I know is that the implantable defibrillator will save you if you have one. But then, if they say, well, I don’t like the thought of having a piece of metal in my chest to keep me alive, you know, I … if God will me to die tomorrow, that is their feeling, then I should die tomorrow. If my time is up, then my time is up. That is their feeling about it. They don’t deserve to be alive.

Gary’s dialogue demonstrates an awareness of the powerful body-emotionality that causes some patients anguish such as, “the next cardiac arrest,” and “having a piece of metal in my chest to keep me alive.” Yet there is no expressed empathy for these patients. The insensitive, judgmental statement, “They don’t deserve to be alive,” was offered for comment to two other participants in this study, a nurse/family member and a cardiologist/ethicist. Both responded with the same descriptor, “I think a statement like that is horrible.” There is substantial concern throughout the medical profession in relation to emotional detachment by physicians (Ford et al., 2000; Rogers, 2002). Thus, humanist courses are being offered to potential physicians that include themes, such as empathy, death and dying, communication, physician emotion, and emotional dilemmas. These themes are taken from the genres of film, literature, and art. It is hoped these courses will lead to more humane physicians in medical practice (Lancaster, Hart & Gardner, 2002).
I asked cardiologist Sean an ontological question, “What does it mean to you to implant the heart of a person with a device that is going to give them an electric shock?” His response was reflective. “Yeah. (Silence). I need to ponder on that … what does it mean to me? Ah, I guess like trying to fix a fuse with a soupspoon. But it is the best soupspoon we have.” Sean’s soupspoon metaphor for a circuit breaker fell short of the ontological answer I hoped for. I suggested the metaphor indicated; “you feel it [implantation] does have its inadequacies.” Sean elaborated.

Oh, yeah. Sure it does, but there is not a better way of doing it [implantation] for the patients who end up getting one [ICD], my patients anyway. That is integral to my beliefs and what my opinions are based on. My experience, the literature, and so on. You know, there is a down side to every procedure. Every device. We try and make the best out of it though. Try to emphasise the positives at all times. It is important for our mental health as well. Many of the patients who get ICDs, I think a lot of them feel as if they are undeserving survivors. You know, I have this thing; it is keeping me alive, whereas I know Uncle Joe and the man down the street just died suddenly. I am going to carry on, while I perhaps feel a bit lonely or strange, special.

Sean’s body-emotionality emanated from a paradox. While in dialogue about a multi-billion dollar market of sophisticated bioelectronics, Sean’s feeling and belief about implantation of a person’s heart with a bioelectronic ICD reduced the technology to the inadequacy of an everyday soupspoon. It was because of these inadequacies that Sean felt the need to be positive and to be protective of his “mental health.” This body-emotionality was also necessary to protect patients who felt survivor guilt, alone in liminal hybridisation, and different. Cardiologist Beau responded to the same ontological question:

Um, it is interesting in that um, its good in that you do fix up peoples’ problems, and that you do have a positive contribution to their lives. Um, really I don’t think about it. I am just concentrating on this being a heart. I do not really think about the person behind, I just concentrate on the heart.

Although mechanistic in perspective, “trying to fix a fuse,” and “fix up peoples’ problems,” ultimately has body-emotionality effects on physicians. Senior physicians recognised that suppression of empathy contributed to high psychological morbidity, emotional burnout, and depersonalisation (Fallowfield, 1995). In life-threatening cardiology Beau expressed “that things do happen [death]. It is disappointing when that happens, but ah, yeah, but you work through it.” I ventured to question, “How does that affect you next time you go into the theatre?” while working through the
Ah, well, ah, (difficulty answering). Yeah, it makes me a little uncertain, but you’ve just got to do it. It just has to happen. You just have to go back into theatre and do it again. And you have got to realise that it could happen the very next time as well, but ah, that is just what you have got to do.

Being-in-the-world of body-emotionality, disappointment and personal uncertainty within life-threatening cardiology engenders considerable stress. Chris McManus, Professor of Psychology and Medical Education, holds that physician burnout is preceded by emotional exhaustion, depersonalisation and decreased professional efficacy. He suggests that physicians employ an ego-defence mechanism, which may account for treating patients as objects rather than as people (Major, 2002). Beau explained that the death of a patient is not discussed between colleagues:

You don’t. The thing you do talk about is discuss the problem that you faced and you just try and work out if there is anything that could be done differently the next time. Would it make a difference? Maybe try and work out why it happened.

I asked if the humanistic value was considered between cardiologists.

Ah, … no. I guess I don’t really. I mean, talking about the case helps get over that sort of … problem. You know, just realising that someone has died, but you deal with it yourself. Ah, I don’t know, um, … um, men just let … just think about everything that you have done and gradually with time it will ah, … you never, never … whenever you think about it, it is still disappointing but I guess it does not have the emotional impact after time passes.

After listening to Beau’s stressful dialogue and the “emotional impact,” Merleau-Ponty’s (1962, p. 160) words seemed appropriate; “In so far as the emotion elects to find its expression in loss of speech, this is because of all bodily functions speech is the most intimately linked with communal existence, or, as we shall put it, with co-existence.” I inquired if Beau was more comfortable with the mechanistic perspective; “Yeah. What we do is very mechanical. The more organised you are, the smoother it goes. It is very hard to think that you are operating on a person and how important that is. That is the way I deal with it. That’s the way I learned.”

Physician and author John Holland (1995) wrote about the demands on a physician’s emotional world when encountering patients on an emotional level. Holland described
the strain that is the very nature of medical work and its impact on a physician’s ontological world. Such is the affective nature of implantation of a person’s heart with a permanent ICD.

Cardiologist and ethicist Neil responded on concerns with the concept of heart implantation with an ICD.

The major concern of the patients is to live as long as possible with an acceptable level of quality of life. They are most often willing to accept the, sometimes painful, electric shocks that the ICD delivers and also other negative effects associated with the therapy. In other words, life is what counts, and an ICD gives them the opportunity to prolong their lives. However, the price to be paid is sometimes a more painful death caused by heart failure. This is undoubtedly a fact that has to be taken into account. One could consider an ICD as a life insurance. It is safe to have that kind of insurance even if it never will come into use. However, sometimes the price is too high.

The emotional turmoil for both patient and cardiologist is given eloquent account in Neil’s dialogue. To be empathic in the daily trauma arising from patients’ anxious search for “an acceptable level of quality of life” involves the cardiologist in a dilemma of body-emotionality. I refer back to cardiologist Sean’s statement of “the sleeping problems of cardiology;” life extension can lead to other life-threatening disease, psychosocial distress, and possibly “a more painful death.” As Neil emphasised “sometimes the price is too high.” This stark reality is never far away in cardiology.

Elizabeth Chapman (2002, p. 195) wrote of quality of life through a phenomenological question; “What is a life worth living?” This issue is body-emotionality as evaluated by the person and not from a medical perspective. The depth of quality of life is often arrived at through comparison to other individuals (Chapman, 2002). Comparison may be a mechanism for establishing a reason for a person’s very existence, especially in the lived-world of implantation. Cardiologist and ethicist Rhys differed in expression from Neil regarding heart implantation. Yet, an alternative interpretation “that they will not die in a proper way” is similar.

I have no objections, as I know that the pacemakers/ICDs have been a great help for many patients. [However] I believe that quite a few [patients] are sceptical. Some because they think that they will not die in a proper way and some because they have experienced that the ICD will give a shock.
While Neil spoke from a sound understanding and knowledge of the patients’ price for delayed mortality, Rhys was less expressive of body-emotionality. Rhys used a convincing “I know,” when referring to implantation and to devices, yet he used a less sure “I believe,” when referring to what patients know.

Emotional responsiveness and emotional expression from physicians is a complicated issue (Lyon, 1996). An exemplar provided by Anderson, Moyle and McAllister (2002) demonstrated how deeply embedded body-emotionality can become in relation to heart implantation and how unemotional a cardiologist can appear when confronted with a patient’s emotion. Such is the nature of heart implantation. Cardiologist Zane expressed concerned body-emotionality from both his perspective and the patient’s perspective.

I think they [patients] consider the ICD as a lifesaver. At the same time, they are afraid of dysfunction of this lifesaver and those who have many shocks hate it at the same time. That is a forbidden feeling - to hate your lifesaver! I am no longer concerned about their high mortality risk because it has been lowered. Instead I think of how to make them feel more comfortable with their treatment. Some have too many shocks to feel good and one or two did also ask for removal of the device despite the increased mortality risk. Others have inappropriate shocks and need customising of the treatment both with pills and device adjustment.

The core of Zane’s dialogue is a paradox or a Pandora’s box of body-emotionality. History and culture outlines numerous situations where people want to be liberated or saved from threat of death and yet develop the emotionality of hating the lifesaver. The lifesaver personifies oppression and fear. Timothy Quill (2001, p. 26) advocated that physicians evaluate the empathy underlying a treatment labelled as ‘for the good of the patient.’ In addition, a combination of empathic imagination and knowledge of the patients’ values and emotions is preferable to imposing the medical worldview in life-threatening illness. Thus, Zane was aware of patient’s feelings of fear and body-emotionality. He sought to work through their perspective rather than his own, in heart implantation and explantation. Cardiologist and ethicist Rhys expressed empathic imagination and understanding when considering the question of patients feeling “enough is enough; I am sure I would explant it or turn it off. It would be like [being] hit by lightning.”
Cardiologist Sean’s summation of body-emotionality followed a question in relation to the heart in the context of literature and lyrics.

That sort of reference is an emotional one. That is a very powerful one, a very powerful one. When you talk about someone’s heart, there are a number of ways you can talk about it. You can talk about it on a psychological level. I feel things in my heart. You can talk about it on a physical level. My heart pumps blood around my body. I think everybody’s concept of their heart is somewhere in between those two aspects.

**IMPLANTATION AS BODY-SPATIALITY-TEMPORALITY**

Within the modalities of body-space and lived-time the cardiologists in this study hoped to hybridise an alliance between a person’s heart and a bioelectronic ICD. However, as this study demonstrates, such an alliance for many patients remains fragile. Merleau-Ponty (1962, p. 124) cautioned:

> We must either reject physiological explanation or admit that it is all-inclusive; either deny consciousness or accept it as comprehensive. We cannot relate certain movements to bodily mechanism and others to consciousness. The body and consciousness are not mutually limiting they can be only parallel.

The mechanistic perspective, of body-space and the intellectualism of lived-time, by cardiologists has been evident in the preceding themes in this chapter. The existential modes of body-space and lived-time continue to be objectified “as long as the body is defined in terms of existence in-itself, it functions uniformly like a mechanism, and as long as the mind is defined in terms of pure existence for-itself, it knows only objects arrayed before it” (Merleau-Ponty, 1962, p. 124).

As I write this chapter, an ICD recipient in this study communicated that his cardiologist had received a shock from the ICD through the recipient’s body. This shock occurred from within the occupied physiological heart-space of the recipient, while the technician tested the bioelectronic timing of the ICD.

> I was doing a stress echo heart test. I reckon I saw and heard it [ICD] go off, but the attendant did not agree with me. It continued to go off, *six shocks in two minutes*. I yelled for the cardiologist to turn the thing [ICD] off which he eventually did. It felt like a sledgehammer on my chest, also the cardiologist attending got a shock when he was laying me down and it went off (Stan).
This is an example of the liminal boundary between cardiologist and patient when the cardiologist can adapt only to physiological space and the mechanistic timing of a stress echocardiography display, in relation to heart implantation. I checked Medline’s Database retrospectively (1990-2002) for documented accounts of physicians receiving shocks from recipient’s ICDs, without success. RN Amy related how a cardiologist suggested during a patient’s VT storm of ninety shocks that “I’d be alright to touch him and I was just like, well, how come you are not? He [cardiologist] has never been one to touch the patients, except with a stethoscope.” Thus, it would appear that cardiologists tend to avoid contact with a person’s body-space implanted with an active ICD. Cardiologist Sean commented on the heart in body-space and the ICD effectiveness over lived-time.

I think it [heart] is a marvellous organ. It continues to amaze me with its reserves and adaptation capabilities. It seemed that a significant difference could be made to somebody’s life, quality or length, or both, at least half the time [with an ICD].

This “half the time” difference to body-spatiality-temporality for patients was instrumental in Sean’s choice to engage in cardiology for his professional lifespan. Unfortunately, as Heidegger (1966, p. 54) cautioned, dependence on technology and human reaction to technology can be engaged in only “insofar as we do not permit them to claim us exclusively and thus to warp, confuse, and finally lay waste to our essence.”

**Being engaged in body-spatiality-temporality**

The intertwining of body-space and lived-time is a universal concept, not absolute, and not perceived as separate dimensions (Capra, 1982). In attempting to establish the notion of body-space-time in life-threatening illness, physician and psychologist Larry Dossey (1982) coined the metaphor of biodance. Biodance conjoins the world-space and movement of the lived-body in a harmonious rhythm of lived-time across the lifespan. Larry Dossey explained in his work titled, Space, Time and Medicine (1982, p. xi).

The spacetime view of health and disease tells us that a vital part of the goal of every therapist is to help the sick person toward a reordering of his[her] world view. We must help him[her] realise that he[she] is a process in spacetime, not an isolated entity who is fragmented from the world of the healthy and who is adrift in flowing time, moving slowly toward extermination. To the extent that we accomplish this task we are healers.
This excerpt captures body-liminality in space and time by acknowledgment of a person in the disorder of illness and biotechnology, such as heart implantation, “who is fragmented from the world” in the liminality of “an isolated entity;” a person “who is adrift” in liminal body-space and liminal lived-time.

I asked cardiologist Sean how he dealt with a patient’s understanding of heart implantation.

Yeah, well, for example with the ablation procedures it is very hard without EP studies, measuring arrhythmias and these things. It is very hard to explain EP studies to the patient without scaring the pants off them (nervous laugh). We are going to put these wires up into your heart and start your fast rhythm, we will make some small measurements and then we will burn it (laugh). Very often a lot of information has to be transferred in a short time. And it often takes 2-3 interviews before you find out what the patient’s understanding is of what they want. It takes them a long time often to assimilate this.

The language application of Sean’s worldview, which deals with “ablation,” “EP studies,” “measurements,” “wires up into your heart,” “fast rhythm,” and “burn it,” could only terrify a person’s consciousness of a continuing ‘rootedness’ in his/her present subjective situation (Merleau-Ponty, 1962). The notion of biodance is surely a worldview gap in spacetime from the cardiologist’s worldview in heart implantation.

Sean continued.

There again, that is where the time aspect comes in. You know, they need a few days at least for percolation of all these interactions and forces. It probably takes about three days to actually get to know the patient to a point where you think that you understand each other adequately. Probably, initially about half an hour, and then come back for an hour at a later time, maybe another half an hour after that at least. [I asked for the patient’s reaction?] Um, well, if someone trusts me then they will see that I will do the right thing by them. And act with integrity and honesty. I tell the patients. I don’t have time to mislead you. That is how it is.

Sean’s excerpt projects body-space suspended in lived-time. A person’s body-space is located in an environment of aloneness within which “forces” of facing mortality and decision-making are in “percolation.” The cardiologist’s time is limited to no-time-to-mislead. Marilyn Chapman (1997, p. 114) wrote about “having in time,” “doing in time,” and “becoming in time.” The patient in the above excerpt is restricted in having time to reorder his/her worldview; the patient can do nothing in the time
allocated that will ease the emotionality of a life-threatening situation; the patient’s
becoming in time unfolds as either being hybridised by heart implantation with a
permanent ICD or being a challenger of mortality. Cardiologist Gary agreed that EP
studies presented a problem.

   It was the EP studies that were the problem not the implantable device itself, but
there are still problems. There are, for patients, once they have the defibrillator.
They are the people particularly if the device goes off a lot. The shocks, they get
a bit upset by that. And then they need a lot of counselling. But ultimately with
time, they all come to accept it.

Timothy Quill (2001) is passionate about non-abandonment being a central obligation
and responsibility of the physician tending patients in life-threatening spacetime.
Non-abandonment is defined by Quill as continuity of care. This means the physician
remains connected in the spatial circumstances of the patient’s subjective, psychosocial,
and physiological problems, so overwhelming that the physician has no moral choice
but to commit to the patient’s needs over time. Gary’s dialogue, “a bit upset,” and
“ultimately with time, they all come to accept it,” appears optimistic, even dissociative,
when compared to the traumatic dialogue in past chapters. Gary acknowledged, “there
is no continuity, they don’t know what is going on.” Similarly, cardiologist Sean was
concerned about “the capacity to apply continuity to their treatment, to finish it off.
That probably has to do, you know, with the mind sort of in overdrive. They are
emotionally aroused. Worrying about when their world is going to fall apart again.”
Such is the nature of lived spacetime in the phenomenon of heart implantation with a
permanent ICD.

Cardiologist Beau presented a mechanistic perspective on cardiologist’s continuity of
care in lived spacetime.

   It is difficult, because we don’t consider it as implanting. We consider that it is
a patient having a problem that we have to deal … I mean a mechanical … ah, so I guess, we … um, that is basically it, the patient has a problem, we deal with
it. What we do is limited I accept that. It is fixing up a problem so the patient is
well. Most problems of the heart are mechanical. Well, from my point of view
they are mechanical problems.

Being “limited” in both lived-space and lived-time was recognised by Alexis de
Tocqueville (1990, p. 508) as early as 1830 in his comment on cultural and personal
limitations; “each [person] is forever thrown back on [self] alone, and there is danger
that he/she may be shut up in the solitude of his/her own heart.” This limited perspective on spacetime in relation to heart implantation appeared evident in the uncertain expression within cardiologist’s dialogue in this study. I probed for more on Beau’s mechanistic perspective; “Is there not more to surviving than just being fixed up?” Beau’s response was more qualitative yet retained elements of the scientific epistemology of “quantity” of lived-spatiality-temporality.

Well, it is quantity of life isn’t it? Quality and quantity of life; they come to us with a problem. We deal with it the best way we can. We are not trained to deal with that. If they do have that problem and they express it to us, well, there are people who are available to deal with it. That is not what we are trained for. I don’t think you have the time now or the expertise to do both. I mean, you can do, you can do … if there is a specific problem, an anxiety disorder or something that needs to be dealt with, you would need to see someone who is an expert in that.

Beau spoke for cardiologists as a group by using the pronouns “we,” and “us.” We and us represented the culture of cardiology that deals with physiological cardiac problems as a mechanistic body-space occupied by technological dependence and instrumentality. Philip Slater (1970, p. 26) wrote of his dissatisfaction with the magnetic draw of technology that imposed the mechanistic willingness to turn to things technological in spacetime rather than to people to find self-actualisation; “One of the major goals of technology is to free us from the necessity of relating to, depending upon, or controlling other people. The more we have succeeded in doing this, the more we have felt disconnected, lonely, unprotected, and unsafe.” Thus, there can be no solace for cardiologist or patient when technology fails to fulfil human subjectivity in heart implantation as lived-spatiality-temporality. Consequently, there are those disillusioned by heart implantation with a permanent ICD who wish to reclaim their body-space-time through explantation.

In order to explore the cardiologist’s perspective on explantation or deactivation of the ICD in body-space-time I asked cardiologist and ethicist Rhys; “At what point in a cardiac patient’s life do you say ‘enough is enough’ in preventing the patient’s chance to die in peace?” Rhys related his perspective and his involvement in this situation.
I have participated in the explantation of an ICD because the patient thought that it was ‘enough.’ He stayed alive several months but without the anguish he experienced earlier. I believe that the patient must decide for himself even though I may have a firm opinion about this kind of therapy. With a DNR [do not resuscitate] order you can either explant the device or make it stop working with a magnet.

In contrast to cardiologist Gary, who was adamant that patients who considered their lifespan had progressed to a natural ending in spacetime, “did not deserve to be alive,” Rhys was more humanistic in his belief, “the patient must decide.” Rhys was prepared to accept that living in anguished spacetime was not quality living from the patient’s perspective. Awareness of body-space and lived-time can be a catalyst for re-examination of choices in relation to life-threatening illness and the limitations of continuity with those choices (Chapman, 1997). Such is the nature of heart implantation that, as cardiologist Zane stated, “Some have too many shocks to feel good and did also ask for removal of the device despite the increased mortality risk.” Similarly, cardiologist and ethicist Neil was concerned that the biodance of spacetime in relation to ICDs was fraught with lack of continuity.

I am planning to do interviews on patients with ICDs, focusing on how they have been, and how they want to be informed, how they look upon the therapy and to what extent they want to influence decisions regarding the withdrawal of it. I feel that it is important to communicate this issue properly with the patient and that this communication is a very important part of the decision-making process.

Although the content of Neil’s dialogue is related to body-relationality, its focus is on spatiality-movement in a temporal context. In other words, the dialogue pertains to that which has been acted upon in the past, and also what would be the desired acting out in the future, in relation to heart implantation and heart explantation. I pursued cardiologist Gary’s perspective on the concept of dying naturally. The question amused him as he responded.

(Smile) … We are all going to die naturally. Do you mean … all I do is make recommendations to you, and I can tell them what I can do for them. But it is up to them to decide if they want to go ahead. And that is elementary. If I have someone in here and they say, look, I don’t want the device because I am totally against devices it is a totally artificial means of maintaining life. That is immaterial. I don’t have any trouble with that.
Gary’s answer invalidated patients’ beliefs. He believed all people “die naturally.” While acknowledging that some patients believe cardiac devices are “a totally artificial means of maintaining life,” he discounted their belief as unimportant. As a cardiologist, it was “elementary,” “immaterial,” and untroublesome to Gary what patients believed about their body-space and lived-time in relation to heart implantation. Spacetime appeared not to matter to Gary, “except in people who have a defibrillator which goes off a lot of the time.” He elaborated by presenting an exemplar of a patient who experienced multiple shocks.

I think it was 70 shocks over the course of a weekend. He wanted the thing [ICD] removed at that point. Now ah, you can remove … we know that this is something that they go through over the course of a week or two, but then, once everything dies down, you control the VT and control the number of shocks they are getting, then they are thinking much more clearly. Then they don’t want it removed.

A further exemplar presented by cardiologist Gary.

There is a patient I am going to implant a new device because he has used up his old device so much. This is a guy who came in a month ago saying he wanted this device out because it is going off so much. But then when he got back to reality and the VT was controlled, he is very concerned that the device is going to deplete, which it is close to depletion, so he does not want … so he is coming in early to have it replaced because he is fearful that it is going to deplete and he will die because the battery will run out before its time.

Gary had already claimed no encounter with any patients who wanted explantation. Therefore there is contradiction in Gary’s dialogue of two exemplars of patients whose subjectivity of their body-space-time led to a preference for natural death. Gary explained this contradiction; “So it is a continuance. You can’t just accept a patient at one place and time and say I have a real problem. Things change over time.” Jeffrey Malpas, Professor of Philosophy (1999), wrote of the conflict between the objective perspective and the subjective perspective in relation to place-time and space-time. Gary’s perspective demonstrated an exclusive, one-way objective worldview that appeared dedicated to the innovation and maintaining of heart implantation with a permanent ICD regardless of others’ subjectivity.

Cardiologist Sean presented a futuristic perspective on implantation as body-spatiality-temporality.
Yes. There is the occasional patient who has a lot of trouble adjusting to the fact that there is a device controlling their heart. I think this is underplayed a lot. I had a patient ring me up a couple of months after [implantation] and say, “can you take it out? I just can’t stand the thought of this controlling my heart.” It is a bit unfair really but … one thing about devices I think they are one step in the evolution of treatment. You know, I don’t think we are going to have pacemakers or ICDs forever. [I asked why?]. Oh, I think there are all sorts of exciting things going on in pacing science at the moment. With gene therapy and implantation of bone marrow cells and things like that. Autonomous transfusions, bone marrow stem cells into the heart. And I can see that can be applied later theoretically to the conduction system. So, maybe not in our lifetime but, later, this will happen. And then there will be a whole other set of issues, why did you do this?

The preceding four interpretive chapters have explored the different perspectives of the four groups who are connected in the study phenomenon of heart implantation with a permanent ICD. The final chapter is the true hermeneutical phenomenological chapter in which implantation may arrive at understanding.
CHAPTER EIGHT

IMPLANTATION: FROM PHENOMENON TO UNDERSTANDING

INTRODUCTION

In this thesis, implantation of the human heart with a permanent bioelectronic implantable cardioverter defibrillator (ICD) has been revealed as a state of being-in-the-world-of-liminality. Liminality has arisen in complex ways to redefine the existential Being of participants in this study. Implantation embraced the cyclical properties of liminality, such as the ritualistic rites of passage; the liminal border of separation between each groups’ life-world; the liminal boundary of hybridisation; the liminal threshold of life and death; and the liminality of being bound in a betwixt and between passage within all the properties of liminality. Implantation crossed the existential boundaries of embodiment, emotionality, sexuality/gender, spatiality/movement, temporality/time, and relationality, as a lived-through state of liminality. Implantation allowed the perpetual push and pull effect across the threshold of life and death: the ultimate liminality (van Gennep, 1960). Moreover, being implanted meant that recipients took on the liminal persona: essentially “neither living nor dead from one aspect, and both living and dead from another. Their condition is one of ambiguity and paradox, a confusion of all (…)” (Turner, 1967, p. 97).

The preceding interpretive chapters explicate that recipients of ICDs, their family members, engaged cardiac nurses and paramedical personnel, and engaged cardiologists, are inextricably connected in implantation by liminal-Being, albeit through different frames of reference. Participants in this study inform our understanding of the phenomenon of heart implantation as the cyclical ontology of liminal-Being: while heart implantation is deemed the treatment of choice for sudden cardiac death (SCD) and life-threatening arrhythmias, existential liminality continues to revolve around Being-in-the-world. Other studies recognising liminality in
life-threatening illness include nosocomial infection (Gardner, 1998), the experience of cancer (Little et al., 1998), and rituals of adversity (Murphy et al., 1988).

This discussion brings together the many experiential features of the phenomenon of implantation in one hermeneutical concept: liminal-Being. Implantation is contextual in that there was liminal-Being before implantation, liminal-Being within implantation, and liminal-Being after implantation. Moreover, liminal-Being includes the existential modes that have framed this study.

**IMPLANTATION AS LIMINAL-BEING**

Throughout this study attention has been drawn to The Liminal Body. The photographic image of implantation represents and illuminates the hybridisation of human-body and cybernetic-body. The biotechnologies involved in creating the x-ray image of recipient, May, altered the ways in which May and others perceived human identity. May was disbelieving and “shocked; my x-ray has to be bionic.” It is as if our technology had surpassed our humanity (Albert Einstein, 2000) or as Donna Haraway (2003, p. 429) concluded: “This is a struggle over life and death, but the boundary between science fiction and social reality is an optical illusion.”

The hybridised image of the chest x-ray created a transparency of May’s body and the reactions of others included embarrassment, feeling sick, being white with shock, and spontaneously turning away. Such reactions unintentionally reinforced and perpetuated a state of liminal-Being. However, these reactions demonstrate the liminal-effect that implantation can have by being observed. How much more trauma is added to liminal-Being for the person who has ownership of implantation?

Recipients drew on popular, science fiction films, such as Alien, Terminator, Robocop, and Star Trek, to identify with their hybrid persons in a way that was culturally known and had meaning for them. Drawing on films assisted recipients of ICDs to verbalise “being wrecked,” and “being destroyed,” by the symbol of implantation: “the thing, the machine.” Noel confirmed that he had “a machine inside him that could do terrible things to his body, and he did not have to like it.” Reid’s phenomenological study (2001, p. 131) reported on two recipients who made similar statements in relation to the
symbol of implantation: the ICD: “something artificial inside [the heart],” and “it is a
prick of a thing. I have no confidence in it at all. I just hate the thing.” Conversely,
other interpretive studies that have used phenomenology (Dickerson, Flaig & Kennedy,
2000; Doolittle & Sauve, 1995), grounded theory (Burke, 1996), and secondary analysis
(Dickerson, 2002b), focus principally on the life-sustaining potential of biotechnology.
While positive reports are undoubtedly valid, there remains a silence that invalidates a
negative experience of bioelectronic heart implantation. Liminal-Being for all
participants originated from an earlier experience with life-threatening arrhythmia or
SCD episode.

Liminal-Being before-implantation

Liminal-Being began for all participants in this study whilst being connected in
implantation on the threshold of life and death. This liminal location threw all involved
into a struggle to forestall sudden cardiac death (SCD). Recipients recounted
lived-through SCD episodes; at least one and at most three events. Other recipients
faced their mortality through the suddenness of arrhythmic-heart-trauma. Whichever
life-threatening trajectory the arrhythmic-heart succumbed to, it “(…) encased the
patient in a visible exoskeleton of powerfully peculiar meanings that the patient must
deal with, as must those of us who are around the patient” (Kleinman, 1988, p. 22). At
the point of SCD, arrhythmic-heart-trauma, or at the moment of diagnosis, the
being-in-the-world that recipients and family members had previously known as
mundane existential living, suddenly joined the liminal notion of ‘dysappearance’
(Leder, 1990).

Powerfully peculiar meanings, embedded in confronting the potential mortality of
existential ‘dysappearance,’ are part of the nature of implantation as liminal-Being. It
was the liminal state of ‘dysappearance’ into SCD and life-threatening cardiac
arrhythmia that prompted recipients to question from an unreachable sub-liminal
consciousness: “What happened?” “Where am I?”

Literally returning from the brink of death is the liminal-trauma of knowing that during
a state of death, however temporal, a person is totally alone. Mortality belongs to the
singular Being. Being alive before SCD represented being-whole, knowing
form-of-body, and directing life’s orientation (Malpas, 1998). As Kara stated, there were dreams, hopes and plans, and all sorts of possibilities to enact and with which to mould self-identity. Surviving SCD and heart arrhythmia made fragile the survivor’s grasp on life and made paradoxical, the meaning-of-the-world. Clinical psychologist, Rick, summarised the philosophy: “it is like starting life all over again.” Thus, as philosopher Jeffrey Malpas (1998, p. 123) explained:

The skein of connections here is tangled: to have a life is to have sense of that life as one’s own and a sense of the world in which that life is lived; and these notions in turn mutually imply a grasp of oneself as existing in and through time (…) including the limits to those possibilities.

Sudden cardiac death allowed people to face the possibility of mortality, however, implantation brings all our existential modes, such as temporality and emotionality, into tension. Recipients were more aware of their existence because of the experience of being on the brink of death, the ultimate-liminality. It would be expected that others, such as participants in randomised control trials and other clinical studies, experienced the tension of their existence. Yet, this existential tension is not explored in randomised clinical trials (RCTs). The authors of these RCTs provide no recognition of the possibility that patients experience deeper, and more subtle adverse effects from SCD and implantation. Researchers could offer much more to humanistic evidence-based practice by extending RCTs to include an arm of interpretive research.

Family members were especially linked to liminal-Being during SCD (Maclean et al., 2003; Mason, 2003). Family members witnessed one of their own succumb to SCD. Such is the psychological trauma of this liminal event that psychological barriers often prevented family members from performing successful resuscitation, even though they had been trained in cardio-pulmonary resuscitation (CPR) (Cooper et al., 2003a). Beth was totally overloaded and unable to recognise the liminal-Being as her sibling during a SCD episode. Instead of performing CPR, Beth was compelled to physically hold on to her sibling as if to prevent losing her loved one across the threshold of life and death. Kara’s children screamed at the liminal-look-of-death in their father’s eyes before Kara threw her spouse to the floor in a traumatic pounding of his body in CPR to forestall SCD. Another spouse captured the liminal threshold of SCD in describing a “fine line” between life and death. Jill’s mother-instinct cast the threshold of life and death as the expletive “Oh! Fuck!” situation when her young child needed to be brought back across
the ultimate liminal threshold. Families experienced SCD and life-threatening arrhythmia in similar ways, yet always as a catastrophic event (Maron, 2000).

Akhtar, Myerburg and Ruskin (1994, p. vii) viewed SCD as an issue of enormous dimensions for all involved. Within the world of cardiology SCD is a problem of liminality that “crosses all categories” of cardiac death, not as a “cause of death, but rather as a specific mechanism of death.” More recently, Batra and Silka (2002) described SCD as a mechanism of death: silent, and multidimensional. Many participants in this study viewed cardiologists’ attitudes to potential SCD negatively. Jay resisted the possibility of implantation for more than a year because of conflicting opinions from cardiologists, which added to his “fear of the unknown.” Stan sought four different opinions on implantation, only to be told by a cardiologist that he was “stuffed.” Unfortunately, no recipient or family member perceived that cardiologists were capable of putting aside the assumption that liminal-Being was other than mechanistic and fixable (Patterson & Zderad, 1976). More recently, intensive care physicians were observed as committed to biotechnology to the extent of claiming: “We’d resuscitate a Big Mac if we could” (Silverman, 1999, p. 86). Without an understanding of the dimensions of SCD, other life-threatening arrhythmias, and heart implantation, nurses and cardiologists often unintentionally overlooked the existential ontology of a person’s liminal-Being.

Reid (2001, p. 249) reported varying descriptors of cardiac nurses interacting with recipients and spouses ranging from excellent to poor. In this study, recipients and family members perceived they were abandoned in their encounters with health professionals. Primarily, it was left to family members to provide physical, emotional, and social sustenance for their loved one who had experienced a life-threatening cardiac event: a situation in which family members felt unsupported by health professionals. Engagement with liminal-Being was portrayed by family members as being beyond cardiac nurses. For example, when parents June and Scott related an incident in the intensive care unit (ICU), their trauma was exacerbated by the absence of cardiac nurses: “Nobody made any attempt to help. [Daughter] was yelling out. She was obviously terribly distressed. There should have been somebody there. Of course there should.” A further example occurred when Kara was alone as she walked up and down outside (ICU), left to believe that her spouse was dead. These and other accounts are
contrary to nursing presence as advocated: “The nurse is not a guide or beacon but rather an inspiring, attentive presence that calls the other to shed light on the meaning of his or her life” (Parse, 1992, p. 40). As the father of a recipient who suffered two SCD episodes, Scott’s summation of nursing care was a commonality across recipients and family members. He did not experience the cardiac nurses he encountered as “(…) a good nurse. There was a little bit, but not what I would think would be good nursing practice for such a complex issue [as implantation].”

**Liminal-Being within-implantation**

Being told by cardiologists that the recommended treatment for a life-threatening cardiac arrhythmia was to have the heart and body hybridised by implantation of a bioelectronic ICD that was capable of delivering electric shock to the heart, was a catastrophic moment in a recipient’s life, in this study. For example, Stan was told that he was “going to have one of these [ICD] in [his heart].” This precipitated an intense emotional reaction in him and staff categorised Stan as “the angry little bloke in the corner.” Another cardiologist announced to Jill’s family that implantation had been decided upon for their twelve-year old daughter. From a dual perspective as a nurse and as a family member Jill’s anger and distress was expressed to the researcher: “How dare we as parents want to make a choice in this decision?” Essentially, families were offered no discussion, and no choice. Implantation was what cardiac nurses and cardiologists knew. Implantation of the heart with a permanent ICD has been politically, economically and scientifically approved, and in many cases already accepted by other health consumers (Burke, 1996). However, no previous study has given an account of the features of heart implantation as perceived by those engaged with and engaged in the implantation experience. Jay’s perspective echoed the viewpoint of other recipients and family members: “Technically and scientifically it is a great success. So that is the attitude of the professionals … technicians!” Thus, in this study, recipients and family members expressed liminal-Being in ways that indicated health professionals had lost sight of their humanity because of the “great success” of bioelectronics.

Cardiac nurses perceived engagement with The Liminal Body as part of their own liminal-Being. This entailed a threshold location in the context of implantation.
Cardiac nurses were betwixt and between the recipient and implantation; betwixt and between the recipient and the cardiologist; and betwixt and between the recipient and bioelectronics. Their being-in-the-world of the implantation persona was a phenomenal field of objects and biotechnologies, such as gowns, masks and sensory overload: “a very frightening experience,” and “a sense of powerlessness that happens” to recipients. Rae summarised all cardiac nurses’ perspectives in this study; “I don’t think we understand exactly what people go through, having an ICD put in. I mean I don’t understand totally either.” Several cardiac nurses spoke of being present in the implantation environment as coldness, vulnerability, lots of light, strange noises, and “machines coming around.”

Important studies, dealing with patients needing nurses who care in such a way that they take time to get to know the patient, advocate a transcendence of biotechnology (Walters, 1994; Wallis, 1998). Expressing caring actions by cardiac nurses is by “communicating, providing comfort, being competent, being committed, having conscience, being confident and being courageous” (Wilkes & Wallis, 1998, p. 582). Being present falls short of being-there for the patient and understanding that the patient is the nurse’s primary concern rather than biotechnology (Melnechenko, 2003). For cardiac nurses implantation meant that engagement with liminal-Being represented part of their own being-in-the-world. Several cardiac nurses expressed empathy for patients described as “imprisoned” and “without control” during heart implantation. Yet, these cardiac nurses found the “monitors,” the video “screen,” and the bioelectronic “wires,” fascinating and preoccupying. In the implantation context, cardiac nurses were unintentional captives “while all this is happening.”

A large, recent study of ICU nurses and physicians (Ferrand, et al., 2003) demonstrated that ICU nurses are significantly denied inclusion in decision-making processes and collaboration in relation to patient treatment and outcomes, in life-threatening illness. Fear of litigation was given as one reason why physicians limit the exchange of information and involvement of competent patients, family members, and nurses, in life-threatening illness. More interpretive research that includes the key players in life-threatening illness could result in less trauma for all concerned.
Within the world of implantation, the presence of used and unused hardware within the heart and body constitutes the very nature of implantation. As The Liminal Body photograph portrays, a person’s body recognises the ‘other’ within and reacts in defence and ‘enframes’ the foreign biotechnology (Feenberg, 2003). Anderson (2000, p. 72) reported in an earlier study how a retired physician described his chest x-ray as “a barbed-wire entanglement,” thus revealing his liminal-Being across all the existential modes-of-Being in this study.

Cardiologist Gary was somewhat affronted when asked how he would feel if he needed an ICD. He concluded that he would not know how he would feel, “until I needed one,” even though he claimed to have implanted hundreds of recipients. Moreover, cardiologist Beau admitted that cardiologists are not trained to deal with emotions, and cardiologist Sean described engagement in implantation as “flicking the switch” emotionally, as a mechanism of protecting the cardiologists’ “mental health.” Alan Mermann, physician and theologian, described many instances where physicians seemingly protected their mental health from the emotion of a patient’s life-threatening illness (Mermann, 1999). For example, a physician stood at the foot of a patient’s bed with folded arms. This physician diagnosed a life-threatening illness and left the room. Leaving-the-room was a contextual metaphor frequently noted by Mermann in his study of physician/patient interaction: the life-threatening illness belonged to the patient while the treatment belonged to the physician. As Mermann (1999, p. 117) explained: (…) “disclosing those innermost parts of ourselves that we know will prove us to be less than we want others to believe us to be (…) many physicians are completely at a loss.”

In implantation it is well disclosed in scientific literature that despite the advances in biotechnological designs and materials, the human body remains resistant to ICD encasement materials through its defence responses (Bracke, Meijer & Van Gelder, 2003; Gradaus, Breithardt & Bocker, 2003). Recipients of bioelectronic cardiac devices in a previous study (Anderson, 2000, p. 77), described implantation as “being pummelled,” and the device as, “it is not a part of me.” Furthermore, during implantation, the biotechnology required the cardiologist to “pummel, push and force” the device within a recipient’s body which left body tissue “black and blue, and swollen.” It would appear that if implantation is to be successful, the cardiologist is rendered the servant of the biotechnology (Fox, 1993). Consequently, “the body
becomes an anonymous part of the equipment; literally faceless and genderless” (Hogle, 1995, p. 211), and humanness becomes liminal-Being.

Engagement in implantation by cardiologists in this study was essentially a dilemma. Cardiologist Sean explained engagement in implantation as a dichotomy: positives and negatives, success and failure, risks and benefits, pluses and minuses, medication and bioelectronics. The final decision regarding implantation involved liminal-Being as a life and death threshold. As Sean summarised: “It is very hard to give them information in a neutral way, because we are all enthusiastic for new technology and um, we think we know what we are doing.” Cardiologist Beau described implantation as “borderline.” Borderline procedures are engagement in liminal-Being because “no matter what you do, somebody is going to die.”

Liminal-Being after-implantation

Merleau-Ponty (1962, p. 352) recognised that human beings experience their existence on many levels because living is intertwined in complex ways: “We have learned in individual perception not to conceive our perspective views as independent of each other. We know that they slip into each other and are brought together finally in the thing.” The phenomenal “thing” in this study, is heart implantation with an ICD. This circumstance brought about a dichotomy within liminal-Being for all participants: recipients experienced life-extension and loss, family members experienced relief and grief, cardiac nurses and cardiologists experienced satisfaction and dilemma.

Implantation with an ICD provided recipients with the possibility of life-extension through the capacity of the device to bioelectronically shock their arrhythmic heart to prevent SCD. As portrayed by Burke (1996, p. 352) “securing life through technology acceptance” is a positive concept. Moreover, regaining life within the context of having limited expectations may be interpreted as acceptance. However, human beings are existential: possessing primal modes-of-Being, that become liminal-Being when experience-of-the-world is threatened, altered, or lost.

For recipients in this study, being-alive highlighted that which was lost within implantation. Dell lost self-direction. Her near-death experience as a child
pre-determined her preparedness to fulfil Ars Moriendo (Lamont, 1973) at the time of her second SCD episode. Dell’s conviction embraced the philosophical question posed by Steiner (1998, p. 18): “Why do you resist the notion that death is already present in the living?” Dell perceived that survival of SCD and implantation was the essence of her liminal-Being. Having prepared for death for half her life, surviving SCD and being denied the choice of heart implantation with an ICD, meant that she felt “destroyed,” “the blackness of depression,” and “was suicidal.” Near-death consciousness is an understudied and possibly undiscussed phenomenon in relation to heart implantation (van Lommel et al., 2001). Conversely, other researchers attach an element of dissociation to near-death experience while generally supporting:

[near-death experience as] a shifting of attention from the physical environment to an altered state of consciousness in which perception, cognitive functioning, emotional states, and sense of identity may be partly or completely disconnected from the mainstream of conscious awareness (Greyson, 2000, p. 463).

All recipients in this study expressed sensitivity to the notions of suicide (Goodare, 2001) and self-harm (Freeth, 2001; Stedman, 2001) that pervaded liminal-Being after implantation, because of the scope of losses each endured. The effect of such losses corresponded with Sylvia Plath’s metaphorical Bell Jar (Plath, 1971). Sylvia Plath’s autobiography described her attempt to escape depression, electroshock therapy, loss of identity, and death by suicide, by retreating beneath the bell jar. Jade could understand the futility of The Bell Jar when she wrote in her journal that her world was an “unfillable emptiness.”

Clinical trials of ICDs rarely mention suicide as part of the attrition report (Arnold & Pairolero, 1990). More recently, following the SCD of three sisters, the suicide of a twenty-one year old female with a prophylactic ICD was reported (Zareba et al., 2003). In the present study one recipient admitted regret at not having prior knowledge of heart implantation and concluded; “I would not have one [ICD].” Similarly, in a previous phenomenological study, Reid (2001, p. 121) reported one recipient who wished to “Take it out! (…) The whole time it’s a constant worry.” After two years, the recipient’s confidence had been undermined by panic, anxiety, and depression. Thus, quality of life (QOL) for recipients and family members has been reported as very much an individual perception in studies on implantation with an ICD (Bainger & Fernsler, 1995; Bremner, McCauley & Axtell, 1993; Dickerson, 2002b; Reid, 2001).
Before implantation recipients and family members in this study and other studies (Reid, McKinley & Nagy, 1999; Reid, 2001) were desperate for information, education and counselling, which was not forthcoming. After implantation, recipients and family members were left to their own devices to a greater extent than before implantation (Reid, 2001). Health professionals were not prepared to deal with post-implantation issues that exacerbated post-traumatic stress in recipients and family members (Cain, 2002; Van der Kolk, 1996). Such issues included short-term and long-term memory loss following SCD (Dougherty, 1994; 1997), and the unresponsiveness of health professionals who perceived that nothing further could be done after-implantation (Anderson, Moyle & McAllister, 2002; Campbell, 2002). While recipients were told that implantation with an ICD was a life-saver, and a life-insurance against death, recipients such as Stan perceived, “That is the end of my life,” and Hugh’s ontological world filled with liminal-Being, “The whole world comes crashing down (…). Not being able … to be what you are.” Reid (2001) reported a recipient questioning the cardiologist when told the ICD was a life-saver, “And how can I die?” The cardiologist laughed, replying: “Oh, you’ll find a way!” Sidestepping the question of mortality shapes an unequal perspective of illness and death (Haraway, 1993). The tenuous connection between life and death issues was often too confronting for health professionals to deal with comfortably. Hence, the role of clinical psychologist Rick became invaluable to many recipients and family members in this study. Much emotional suffering and damage could have been alleviated earlier if Rick had been routinely included as a member of the cardiology team.

After implantation further losses to liminal-Being for recipients in this study lay ahead. Seven recipients lost professions and the remaining two recipients were constrained within their livelihood because of the risk of ICD malfunction as a result of interference from electromagnetic forces (Chiladakis et al., 2001; Dawson et al., 2002; Kolb, Srenner & Schmitt, 2001; 2003; Pinski & Trohman, 2002; Scholten & Sily, 2001) that command human environments (Kolb et al., 2003). Loss of life-security for recipients and family members added to the grief and trauma that already existed.

Cardiac nurses in this study who had access to a referral system were able to mobilise the services of a clinical psychologist as part of a follow-up service for recipients and
their families. However, cardiac nurses in contact with the recipients in this study perceived they were constrained and professionally at risk. One cardiac nurse felt the constraints of practice in that “A lot of things fall through the cracks.” Consequently, she was relieved to go home each day and “leave it all behind.” Another cardiac nurse perceived that too many ICDs were implanted and hoped that the situation would eventually be “re-examined” in relation to unnecessary implantation. These concerns, questions, and dilemmas, for cardiac nurses were summarised by Sue who viewed some aspects of implantation as “horrible.” However, she did not express her opinions because, “I wouldn’t have a job if I did that.”

As one father, Scott, explained gaining access to clinical psychologist Rick required “a stand up fight.” Furthermore, cardiologists perceived the psychosocial effects of implantation as outside their realm of saving lives. In fact, some cardiologists did not acknowledge the validity of the psychological effects of heart implantation. For example, one cardiologist perceived a “huge [monetary] payout” as a benefit of heart implantation with an ICD. Stan expressed this encounter with the cardiologist who did not understand that nothing could ease the loss and grief within liminal-Being, when Stan lost the profession that “he loved.”

In this study the ever-present risk of infection became part of liminal-Being for two recipients and their family members in this study. Infected implantation exuded devastation and further invasive ‘other’ as being-in-the-world (Anderson, 2000; Gardner, 1998). Implantation-related infection is one of the leading body-hazards classified by many scientific studies on ICDs (Kron et al., 2001; Mela et al., 2001). An under-researched source of infection is refurbishment of devices (Ryden, 1998). Previous studies have not dealt with how the person experiences infection, in relation to heart implantation. However, two recipients in this study significantly detailed the liminal-Being of post-implantation infection as “devastating.” Similarly, a recipient in a smaller study by Anderson (2003) used the same descriptor for post-implantation infection.

Implantation continued to be experienced as liminal-Being for all participants in this study. The permanency of implantation was ever-present in the potential of shock therapy that meant a heightened state of vigilance for recipients in all facets of everyday
Some recipients experienced occasional shock therapy while others experienced frequent shock therapy, and still others were subjected to electrical storm (Adler et al., 2001; Greene et al., 2000; Korte et al., 2000). Each situation has its own degree of ‘unknown-ness.’ The recipient cannot become complacent about implantation, as Jock concluded, “It is only a matter of time.” For those subjected to frequent shocks or an electrical storm, the concept of nemesis (Midgley, 2003) was real. Simon perceived that the shocks were a punishment, which he had done nothing to deserve. Mary Midgley’s (2003, p. 145) philosophy on nemesis was appropriate in analogy: “Any approach to total paralysis, total solitude, total destitution, total monotony, total confusion, universal hostility, is serious for anybody.”

Family members experienced the constancy of implantation by being ever vigilant, due to anticipatory grief. Family members’ liminal-Being emanated from constantly living-through-implantation in that it represented the paradox of retrieving their loved one from SCD, only to be estranged on the outside of implantation. Their loved one returned to them as a stranger, a different person: “It did not look like her.” Family members were targets of liminal-Being through anger, resentment, and distrust, because some recipients would have chosen to die one time only (Watt, 2000). As Jock explained, he was living his third life and this meant that mortality was ever-present, to be faced again. This situation of liminal-Being has been termed, “walking the edges” (Cairns, Thompson & Wainwright, 2003, p. 287). Family members became victims of implantation through their anticipatory grief. There existed a degree of compulsion to be over-protective of recipients by providing at times a misunderstood surveillance (Eckert & Jones, 2002). Constancy was aptly described as: “Grief is like a stranger who has come to stay in both the heart and the mind” (Staudacher, 1987, p. 4). Cardiac nurses and cardiologists also experienced being-on-the-outside as liminal-Being.

Cardiac nurses and cardiologists cannot avoid their own liminal-Being in the loss of authenticity when a recipient reacts with a statement, such as: “You don’t know what I am going through.” Cardiac nurses and cardiologists were perceived as the eyes above the masks in the procedure of implantation. Recipients and family members retained this inhuman image associated with implantation. Future encounters with health professionals elicited a posttraumatic stress response. Such elicitation of a posttraumatic stress response is also discussed by Van der Kolk (1996) in his study of
trauma. In implantation the intention of cardiac nurses and cardiologists was to enact the well-known prayer by Reinhold Niebuhr: “Give me the courage to change the things which can be changed. And give me the patience to accept the thing that cannot be changed. But most of all, give me the wisdom to know the difference” (cited in Pojman, 1992, p. 35). However, the strain of human intention often belies the depth of how “it is very hard to think that you are operating on a person and how important that is,” as cardiologist Beau expressed. A life-sustaining therapy, such as implantation with an ICD, can be extraordinary for all involved because it is a life and death issue, it is hazardous, terrifying, invasive, disruptive, (Watt, 2000) and as cardiologist and ethicist Neil stated, “sometimes the price is too high” in human terms.

This study demonstrated similarities with a report on how cardiologists can present as unemotional and non-supporting when required to deal with liminal-Being, especially that of a patient’s shock diagnosis, such as implantation (Anderson, Moyle & McAllister, 2002). One patient in Anderson’s study relayed a series of physical activities within his capability in an attempt to convince the cardiologist that implantation with a bioelectronic device was unnecessary. However, the patient was ignored, dismissed, and left feeling: “it was just like being hit in the face with a wet sponge” (p. 29). Similarly, the power of biotechnology can be used as a strategy to dismiss anxious cardiac patients. Daly and McDonald (1993, p. 91) reported that cardiologists used echocardiographs as a persuasive tool to induce compliance in patients. The echocardiograph served to control the medical encounter and to secure the patient’s trust and acceptance of “technically determined reassurance.” Anxious patients needed reassurance, thus the technological test was the strategy used to communicate that something was being done.

The depth of liminal-Being in relation to implantation in this study is overwhelming. The descriptors, such as anxiety, panic, shock, hate, anger, and many more, permeated the dialogue of recipients and family members to an extent that they perceived was insufficient to adequately describe the experience in its existential complexity. Liminal-Being, as a concept embracing all that is unreachable, “indescribable and undiscussable” (Bar-On, 1999, p. 1), captures the imagination of the reader as recipients and family members struggled to contend with living on the edge of death every moment in time. As one recipient stated: “We never, ever discussed the fear.”
Cardiac nurses and cardiologists are subject to the same mortal fear as recipients and family members, yet efforts to understand liminal-Being within them and others, were not always evident in this study. There was an anticipatory fear of hovering death that swallowed up even the most stoic attempt to deny Being (Cairns, Thompson & Wainwright, 2003). The symbols of heart implantation, the machines, the monitors, the ICD, were all paraphernalia of looming liminal-Being, and all involved in implantation were subject to grief, loss and death, albeit from differing perspectives.

Many of the cardiac nurses connected with the idiomatic uses of the word ‘heart,’ tabled in Chapter one, and several had witnessed “gob-smacking” examples of ‘the broken heart phenomenon’ recognized by psychologists (O’Conner, Allen & Kaszniak, 2002). Clinical psychologist Rick was well experienced in counselling recipients and family members after-implantation. He spoke of how modern biotechnology fundamentally altered the level on which health professionals communicated with patients. There was the potential for science fiction as reality and for death to be viewed as more and more remote. There was a moral dilemma for all concerned in implantation. Rick emphasised that some people “can’t live like that.” Over centuries views on death have altered little since the ancient philosopher Seneca (A.D.3-65) cited by philosopher Louis Pojman (1992, p. 34) wrote:

> Life has carried some men with the greatest rapidity to the harbour, the harbour they were bound to reach if they tarried on the way, while others it has fretted and harassed. To such a life, as you are aware, one should not always cling. For mere living is not a good, but living well. Accordingly, the wise man will live as long as he ought, not as long as he can. He will mark in what place, with whom, and how he is to conduct his existence, and what he is about to do. He always reflects concerning the quality, and not the quantity of his life. As soon as there are many events in his life that give him trouble and disturb his peace of mind, he sets himself free. And this privilege is his, not only when the crisis is upon him but as soon as Fortune seems to be playing him false; then he looks about carefully and sees whether he ought, or ought not, to end his life on that account. He does not regard death with fear, as if it were a great loss: for no man can lose very much when but a driblet remains. It is not a question of dying earlier or later, but of dying well or ill. And dying well means escape from the danger of living ill.

Cardiologist and ethicist Neil perceived that a person’s ontological intention in-the-world includes, “to live as long as possible with an acceptable level of quality of life.” In contrast, a general practitioner posed an uninformed question to the spouse of a
recipient of an ICD, “you mean he is never going to die?” The ontology of a person cannot be understood outside the life that is the unique person and the existential modes-of-Being that make up that life (Malpas, 1998). Liminal-Being through implantation breaks down the existential continuity between the elements of a recipient’s life, such as family and profession. This existential break-down is the end of known ontology and the beginning of an unknown ontology: it is a ceasing-to-be. Thus, the severe trauma of heart implantation with a permanent ICD may be viewed literally as, no less the end of a recipient’s subjective life, than the actual death of the objective body. Dell captured ‘ceasing-to-be’ in her statement: “I have had three different lives. (…) I was praying to be dead.” In essence, the projects, events, and desires, about which Merleau-Ponty (1962) wrote, are essentially at an end, without an end to the living body. There is meaning in Malpas’ philosophy that is analogous with palliative philosophy. Thus, implantation evokes the question, “What meaning can health professionals incorporate into interacting with recipients and family members that will build upon evidence-based practice in relation to implantation with life-extending ICDs?”

FURTHER REFLECTIONS FLOWING FROM THE FINDINGS OF THIS STUDY

“We are discussing no small matter, but the way we ought to live.” – Socrates

This research is a human-science project. As such, it was not intended to be generalisable across other research populations. This may be considered by some researchers to be a limitation. Included in the strength and value of a humanistic approach to research, is that if the research is conducted and reported in a sufficiently rigorous manner the findings will be transferable to other groups. In this part of the thesis further reflections on the findings of the study will be presented with suggestions for how these findings may be transferred to those who live with life-threatening illness, their family members and the health professionals who care for them.

The results of empirical research, such as RCTs, identify that there are significant sequelae in relation to biological hazards, psychosocial hazards, and quality-of-life hazards that range across the phenomenon of heart implantation with an ICD. Other
studies expand on this knowledge by classifying and categorising the identified hazards in RCTs. The knowledge already accumulated needs to be further expanded to include the humanistic issues of existential experience. Human research that emanates directly from the lived-world of key players who experience ICD hazards from different worldviews can provide insight into the experience of recipients and their family members and as such can deepen the awareness of health professionals. In this way, the service of health professionals could be less fragmented and hence, move forward to ameliorate an area of practice in cardiology that is lacking: both in understanding and in advocacy.

Findings from the present study reveal that life-threatening cardiac trauma triggered an existential crisis for all participants. This included the whole person: the physical, emotional, psychological, social, spiritual, and cultural beliefs, in relation to the meaning of implanting the heart. The findings of this study revealed a fragmented service by health professionals, which contributed to professional frustration, professional constraints, professional dilemmas, and professional loss of authenticity.

The present study, together with previous studies, has provided a body of evidence that shows how health professionals perceive engaging with and engaging in heart implantation with a bioelectronic ICD. As previously stated, health professionals perceive that life-extension lies within hybridisation: the alliance of body and bioelectronics. Sudden cardiac death episodes and life-threatening cardiac arrhythmias are treated as emergencies that require a curative direction towards heart implantation with an ICD. However, as health professionals in this study have stated, implantation with an ICD is not a cure, and often it is not even a solution for improving a person’s long-term quality of life. This indicates that health professionals are beginning to question the appropriateness of using implantation with an ICD as the first line treatment in all cases. Yet health professionals are confined within the boundaries of the status quo to implant bioelectronics (Sandison et al., 2001).

Cardiac nurses, especially, recognised the value of patient choice as a result of being fully informed in relation to implantation. Cardiac nurses also recognised that the absence of being-fully-informed is part of the nature of heart implantation with an ICD. Despite their efforts, cardiac nurses were overwhelmed with “not enough time” to
prepare recipients and family members for a life-changing event within which their quality-of-life (QOL) would never be the same. The complexities of QOL are unique to each individual to the extent that cardiac nurses require the professional authority of referral to a clinical psychologist. An area that is not addressed by health professionals in relation to heart implantation is the philosophical approach of palliation. Some recipients expressed that being-fully-informed would have resulted in choosing to live without heart implantation. This is the essence of choice and refusing a life-extending therapy, such as heart implantation is part of palliative philosophy. Explantation of the ICD because of poor QOL also emerged as part of the essence of implantation and thus locates the non-recipient in the palliative paradigm.

Critical care nurses from Australia and the United States of America have formed The InnoVision Group through a study by Davidson et al., (2003) that proposed the potential for palliative philosophy to be embraced in the long-term care of patients with life-threatening cardiorespiratory diagnoses. As Davidson’s study shows, health professionals are inadequately prepared to deal with the constant presence of potential death and dying. In addition, Davidson’s study advocated that palliative philosophy could benefit health professionals because there was a search for structure and meaning in the dying experience; negotiation, planning and treatment was not person-focused; and there was health professional discomfort in dealing with death and dying.

With cardiac-related illness listed as the world’s most prominent cause of death, all participants could have benefited from the availability of a team of health professionals to deal with moving beyond the physical, the science, the bioelectronics, to focus on the person and the family members. Within such a team cardiac nurses want “to be equal partners in cardiology,” because they experience an empathic hope for recipients and family members which disintegrates into the futility of frustration and dilemma. Within such a team, the inclusion of a clinical psychologist is an imperative because the task of one-to-one interaction is time consuming and specialised. A clinical psychologist, conducting individual, family or group consultations is person-focused and removed from the fascination of bioelectronics. A clinical psychologist could provide the time required to assist potential recipients, recipients and family members to arrive at self-determination according to their beliefs and values on life and death issues. In other words, to arrive at what the person wants to do.
Advocating patient-based practice

Cairns, Thompson and Wainwright (2003) discussed the impact of being-a-patient through life-threatening illness. Patients and family members are confronted with health professionals who have an unfamiliar culture, unfamiliar terminology, and overwhelming biotechnology. There is distrust of and hesitancy in handing over the life a person perceives may be out of control. Cardiac nurses could be more helpful with these patients if they were trained in specific counselling techniques. Dealing with triggers of fear and vulnerability, such as SCD, cardiac nurses require the counselling and negotiation skills needed by recipients and family members. In this study, none of the cardiac nurses stated possessing any additional or specialised training in counselling, yet throughout their careers they deal with death and dying. Some cardiac nurses described themselves as educators but recipients and family members used the descriptor “technicians.”

Cardiac nurses and cardiologists risk becoming adversaries of patients and family members when bioelectronics is perceived to be more highly valued than quality of life. Timothy Quill (2001, p. 49) provided an outline of negotiation that could benefit health professionals in a time of critical decision-making in relation to heart implantation with a permanent ICD. The following principles on different frames of reference could assist patients and family members to participate in interactive information access and discussion. These principles are inclusive of the key players in implantation, rather than exclusive of recipients and family members.

- Listen and learn about each other’s position
- Separate the person from the problem
- Invent solutions of mutual gain
- Call in a third party: For example, a clinical psychologist or nurse counsellor
- Take a ‘time-out’
- Give in on nonessential areas
- Explore the likely effects of each choice
- Know your bottom line

Research demonstrates that physicians have inadequate understanding of their patients’ beliefs and values with regard to life-threatening illness and decision-making
Negotiation between the key players in heart implantation with an ICD requires a dialogue to achieve consensus-based decision-making that is acceptable for all concerned. In negotiation, the dialogue of decision-making is designed to achieve an understanding of the diagnosis and the prognosis; it is designed to discuss the benefits and the burdens of different treatment options and different frames of reference. All participants are required to understand the meaning of emotionally charged terms, such as “permanent,” “life-threatening,” and “electric shock.” Negotiation requires reaching a preference for treatment that maximises human dignity and quality-of-life, based on guidance and support according to evidence-based practice.

Alternative treatments for SCD episodes and life-threatening arrhythmias, that are currently under trial, include the at-home defibrillator (Stolberg, 2002), and the defibrillator vest (Gessman, 2003). These alternatives may allow patients and family members a period of ‘time-out,’ which enable families to remain in control of the decision-making. During ‘time-out,’ patients and families can reach long-term decisions through their chosen support source, such as a nurse counsellor or clinical psychologist. Unfortunately, in this study, cardiac nurses felt time-constrained and unauthorised to enter into any negotiation. Gay summarised the cardiac nurse situation: “At the end of the day, when you go to educate this patient, you are telling them they are prone to dying. I can’t get round that, no matter if I dress it up or dress it down.” Thus, the findings of this study indicate that this area of cardiology is lacking in support for all the key players in heart implantation with an ICD.

Support groups are viewed as one of the most powerful intervention sources for patients and family members struggling with the effects of life-threatening illness (Lugton, 2002). The support group involved in this study is the only group catering for recipients of ICDs and family members in one state within Australia. In another state of Australia, there are two support groups, one of which meets just once a year. More humanistic studies are needed so that the key players in heart implantation will be more aware of the support needs that have been explored in the present study. As the incidence of heart implantation with an ICD increases, it is evident from the findings of this study that existential-liminality is an ontology that prevented the key players from reaching understanding and hope. There will always be a liminal threshold between life and
death, but that need not prevent the key players in heart implantation from seeking and finding empathic sources of support and hope of understanding. The value of this study lies in the hope that the exploration of heart implantation with an ICD will bring the key players one step closer to understanding this phenomenon. As David Kessler wrote, cited in Cotter (1999, p. 321): “Hope is a journey, not a destination; its value lies in the exploration. Hope is the way we live life and the journey of hope should last until we end.”

**Continuing research**

As a beginning, researchers could be more innovative with their research design. Numerous RCTs have shown that recipients of ICDs will survive longer than non-recipients treated with medication. Having established the efficacy of ICDs, health science researchers have, thus far, avoided changing the research questions. There is the potential to develop and enrich the extension of life with bioelectronics by following through with research questions that explore bio-psycho-social hazards, associated with implantation, the human toll these hazards extract, and ways in which the traumas of implantation can be reduced. Health science researchers have not yet completed their task while there are participants in studies, such as the present study, who are concerned, worried, questioning, and experiencing dilemmas. As one family member expressed it, “(…) the medical people must address this problem. They are just losing half the battle.”

**Possibilities for further research**

While many areas of concern in relation to heart implantation with a permanent bioelectronic ICD have been discussed in this thesis, there remains a need for further humanistic research projects that focus on specific groups. This recommendation is not intended to categorise the human dimension of heart implantation with an ICD, but to inspire other researchers to pursue an area of concern that will add to existing knowledge and enhance hermeneutical understanding in relation to heart implantation.

The dialogue of all participants in this study reveals a need for further research on the impact that is sustained, especially by recipients, from the physical hazards and surgical
complications of heart implantation with an ICD. How does the recipient of an ICD experience his/her body with a nosocomial infection? What is the existential experience of the recipient of an ICD during electrical storm? The possibility for humanistic research with recipients’ body-experience is beyond the scope of recommendations. Other key players in heart implantation with an ICD are also physically involved, as shown in this study, especially family members who witness and attend to SCD.

Mental health issues, such as depression, suicide, dilemma, fear, and detachment, for all key players in heart implantation with an ICD are wide open to humanistic research. What are the support needs of key players in relation to heart implantation with an ICD? This has been illuminated through the dialogue of all participants in this study. By contrast, there are those key players who transcend the negative aspects of heart implantation and become existentially positive. More humanistic research with these players is imperative if a multi-billion dollar industry is to remain morally justified. In addition, evaluation of the effectiveness of clinical interventions designed to moderate the devastating psycho-emotional effects of liminal-Being would seem imperative now these effects have been clearly identified.

In this study I was personally surprised at the socio-cultural influences that were contained in all participants’ dialogue. I believe that research projects incorporating ethnographic or ethnomethodological approaches could provide deeper insights into these socio-cultural aspects of implantation with an ICD.
APPENDIX A

THE IMPLANTABLE CARDIOVERTER DEFIBRILLATOR WITHIN THE BODY
# APPENDIX B

## TABLE OF ICD IMPLANTS

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>New</th>
<th>Rep</th>
<th>NIMP</th>
<th>CD</th>
<th>DCCD</th>
<th>BiVentCD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AUSTRALIA</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New South Wales (20 Centres)</td>
<td>472</td>
<td>379</td>
<td>93</td>
<td>54</td>
<td>58</td>
<td>41</td>
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<td>Victoria (16 Centres)</td>
<td>289</td>
<td>236</td>
<td>53</td>
<td>49</td>
<td>49</td>
<td>46</td>
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<tr>
<td>Queensland (6 Centres)</td>
<td>230</td>
<td>200</td>
<td>30</td>
<td>54</td>
<td>37</td>
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<td>13</td>
</tr>
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<td>South Australia (6 Centres)</td>
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<td>14</td>
<td>53</td>
<td>55</td>
<td>36</td>
<td>9</td>
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<tr>
<td>Western Australia (5 Centres)</td>
<td>55</td>
<td>49</td>
<td>6</td>
<td>25</td>
<td>51</td>
<td>44</td>
<td>5</td>
</tr>
<tr>
<td>Tasmania (3 Centres)</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td></td>
<td>100</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL 2001</strong> (56 Centres)</td>
<td>1155</td>
<td>956</td>
<td>199</td>
<td>49</td>
<td>51</td>
<td>44</td>
<td>5</td>
</tr>
<tr>
<td><strong>TOTAL 1997</strong> (26 Centres)</td>
<td>519</td>
<td>449</td>
<td>70</td>
<td>24</td>
<td></td>
<td></td>
<td></td>
</tr>
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</table>

**NEW ZEALAND**

<table>
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<tr>
<th></th>
<th>Total</th>
<th>New</th>
<th>Rep</th>
<th>NIMP</th>
<th>CD</th>
<th>DCCD</th>
<th>BiVentCD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TOTAL 2001</strong> (4 Centres)</td>
<td>114</td>
<td>86</td>
<td>28</td>
<td>23</td>
<td>58</td>
<td>42</td>
<td>0</td>
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<tr>
<td><strong>TOTAL 1997</strong> (3 Centres)</td>
<td>43</td>
<td>31</td>
<td>12</td>
<td>8</td>
<td></td>
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</tr>
</tbody>
</table>

**Legend:**
- Rep = Replacements
- NIMP = New Implants per Million Population
- CD = Cardioverter Defibrillator
- DCCD = Dual-chamber Cardioverter Defibrillator
- BiVentCD = Biventricular Cardioverter Defibrillator

(Mond, 2003)
<table>
<thead>
<tr>
<th>Early complications related to heart implantation with an ICD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Venous access</td>
</tr>
<tr>
<td>Pneumothorax</td>
</tr>
<tr>
<td>Hemothorax</td>
</tr>
<tr>
<td>Air embolism</td>
</tr>
<tr>
<td>Lead</td>
</tr>
<tr>
<td>Perforation</td>
</tr>
<tr>
<td>Malposition – Diaphragmatic stimulation</td>
</tr>
<tr>
<td>Dislodgment</td>
</tr>
<tr>
<td>Pocket</td>
</tr>
<tr>
<td>Haematoma</td>
</tr>
<tr>
<td>Infection</td>
</tr>
<tr>
<td>Wound dehiscence</td>
</tr>
<tr>
<td>Pain</td>
</tr>
<tr>
<td>Generator</td>
</tr>
<tr>
<td>Loose set screw</td>
</tr>
<tr>
<td>Delayed complications</td>
</tr>
<tr>
<td>Lead</td>
</tr>
<tr>
<td>Venous thrombosis/superior vena cava syndrome</td>
</tr>
<tr>
<td>Exit block</td>
</tr>
<tr>
<td>Insulation failure</td>
</tr>
<tr>
<td>Conductor fracture</td>
</tr>
<tr>
<td>Pocket lead infection</td>
</tr>
<tr>
<td>Endocarditis</td>
</tr>
<tr>
<td>Generator</td>
</tr>
<tr>
<td>Erosion</td>
</tr>
<tr>
<td>Device migration</td>
</tr>
<tr>
<td>Externally mediated damage (trauma, radiation)</td>
</tr>
<tr>
<td>Device function</td>
</tr>
<tr>
<td>Pacing/sensing</td>
</tr>
<tr>
<td>Oversensing</td>
</tr>
<tr>
<td>Undersensing</td>
</tr>
<tr>
<td>Crosstalk</td>
</tr>
<tr>
<td>ICD specific</td>
</tr>
<tr>
<td>Failure to deliver therapy</td>
</tr>
<tr>
<td>Ineffective therapy</td>
</tr>
<tr>
<td>Inappropriate therapy</td>
</tr>
<tr>
<td>Device proarrhythmnia</td>
</tr>
<tr>
<td>Psychological problems</td>
</tr>
</tbody>
</table>

Electromagnetic interference

Adapted from Pavia & Wilkoff (2001).
APPENDIX D

INFORMED CONSENT FORM

GRIFFITH UNIVERSITY

INFORMED CONSENT FORM
Recipient/Family Member/Health Professional

I have read the contents of this informed consent form and have been encouraged to ask questions. I have received answers to questions to my satisfaction. I have received a copy of the Study Information Sheet for my records and future reference. I agree to participate in the “Implantation of a person’s heart with a permanent bio-electronic device: A phenomenological study” project and give my consent freely. I understand that the study will be carried out as described in the information statement, a copy of which I have retained. I realise that whether or not I decide to participate is my decision and will not affect my continued treatment [profession]. I also realise that I can withdraw from the study at any time and that I do not have to give any reasons for withdrawing. I have had all questions answered to my satisfaction.

Signatures:

.................................................................                         ...................................
Investigator                                                                            Date

.................................................................                         ...................................
Participant                                                                           Date
APPENDIX E

GRIFFITH UNIVERSITY
STUDY INFORMATION SHEET
RECIPIENT

Chief Investigator:  Associate Professor Marianne Wallis RN PhD
School of Nursing and Health
Gold Coast Campus
Ph:  07 5552 8759

Co-Investigators:  Carole Anderson RN Phd Candidate
School of Nursing and Health
Gold Coast Campus
Ph:  Free Call 1800 90 5900 Pin No: 9782

Dr. Winsome St.John RN PhD
School of Nursing and Health
Gold Coast Campus
Ph:  07 5552 8935

Project Title:  What is implantation of a person’s heart with a permanent bio-electronic device: A phenomenological study.

The purpose of this study is to understand the experience of living with an ICD implanted within your body and heart.

You are being asked to participate in a research study because you live with an implantable cardioverter defibrillator (ICD) within your heart. The study is part of the doctoral program of one of the investigators, Carole Anderson, who is an experienced cardiac nurse and counsellor. You are invited to read this form carefully and ask Ms Anderson any questions that you may have before making a decision whether or not to participate. This form contains important information and telephone numbers, and you will be given a copy to refer to as the study proceeds.

The study will consist of in-depth conversational style interviews with Ms Anderson at your home or a venue of your choice and at your convenience. Telephone interviews are also an option. Your permission to interview a family member if possible is requested. You will be asked questions about your experience of living with an ICD, about how you feel about the device, how it alters your life, how you manage the ICD, and what problems you experience and solutions you might suggest related to your activities of daily living. A few general questions also will be asked, such as your age and medical diagnosis. There will be two interviews, each lasting more or less than an hour with several weeks between interviews. The interviews will be audiotape recorded with your permission and Ms Anderson will be taking brief notes. Most questions will
be open-ended allowing you to tell your own story. Ms Anderson will be discussing with you summaries of previous interviews at subsequent interviews so that you can clarify or confirm the accuracy of her understanding of those discussions. In addition, if you wish, you may read and discuss the written transcripts of your interviews with Ms Anderson. Feedback in the form of a summary will be provided to you at the end of the study. It is expected that there will be no physical risk from your participation in this study. There is just a very small emotional risk that discussion of your heart condition could be upsetting to you. You have the right to end any conversation at any time. If you wish, Ms Anderson will give you details of a counselor you can contact.

You may gain no direct benefit from the study. However, you may find participation in this study validating. Knowledge about the experience of living with an ICD implanted within the body and heart will be used to inform health professionals and to improve the quality of health care.

Every effort will be made to maintain confidentiality. The results of this research study will be presented at meetings and in publication; however, your identity, description and location will not be disclosed. No information that may identify you will be disclosed to anyone other than the researchers. All interview forms, audiotapes and transcriptions from the interviews will contain a pseudonym and this information will be locked away.

Participation in this study is voluntary. Prior to each interview, there will be an opportunity for you to ask questions about your continued participation in this study. You are free not to participate or to withdraw at any time, for whatever reason. Your withdrawal will not affect your nursing or medical care. In the event that you do withdraw from this study, the information you have already provided will be kept in a confidential manner.

For more information concerning this research you are free to contact the Chief Investigator, Associate Professor Marianne Wallis on 07 5552 8728. If you have any concerns, please contact Ms Anderson. If you have any questions about your rights as a research participant, you may contact:

University’s Research Ethics Officer,  
Office for Research,  
Bray Centre, Griffith University,  
Kessels Road, Nathan, Qld. 4111  
Ph: 07 3875 7111

Griffith University gratefully acknowledges the support you have provided to its research initiatives.
Chief Investigator: Associate Professor Marianne Wallis RN PhD  
School of Nursing and Health  
Gold Coast Campus  
Ph: 07 5552 8728

Co-Investigators:  
Carole Anderson RN Phd Candidate  
School of Nursing and Health  
Gold Coast Campus  
Ph: Free Call 1800 90 5900 Pin No: 9782

Dr. Winsome St.John RN PhD  
School of Nursing and Health  
Gold Coast Campus  
Ph: 07 5552 8935

Project Title: What is implantation of a person’s heart with a permanent  
bio-electronic device: A phenomenological study.

The purpose of this study is to understand the experience of living with an ICD  
implanted within the person’s body and heart.

You are being asked to participate in a research study because you live with, or near to,  
a family member who lives with an ICD within their body and heart. The study is part  
of the doctoral program of one of the investigators, Carole Anderson, who is an  
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your home or a venue of your choice and at your convenience. Telephone interviews  
are also an option. You will be asked questions about your experience of living close to  
a person with an ICD, about how you feel about the device, how it alters your life, how  
you manage your situation, what problems or concerns you experience, and what  
solutions you might suggest related to your activities of daily living. A few general  
questions also will be asked, such as your age and medical diagnosis. There will be two  
interviews, each lasting more or less than an hour with several weeks between  
interviews. The interviews will be audiotape recorded with your permission and Ms  
Anderson will be taking brief notes. Most questions will be open-ended allowing you to
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You may gain no direct benefit from the study. However, you may find participation in this study validating. Knowledge about the experience of living close to a person with an ICD implanted within the body and heart will be used to inform health professionals and to improve the quality of health care.

Every effort will be made to maintain confidentiality. The results of this research study will be presented at meetings and in publication; however, your identity, description and location will not be disclosed. No information that may identify you will be disclosed to anyone other than the researchers. All interview forms, audiotapes and transcriptions from the interviews will contain a pseudonym and this information will be locked away.

Participation in this study is voluntary. Prior to each interview, there will be an opportunity for you to ask questions about your continued participation in this study. You are free not to participate or to withdraw at any time, for whatever reason. Your withdrawal will not affect your nursing or medical care. In the event that you do withdraw from this study, the information you have already provided will be kept in a confidential manner.

For more information concerning this research you are free to contact the Chief Investigator, Associate Professor Marianne Wallis on 07 5552 8728. If you have any concerns, please contact Ms Anderson. If you have any questions about your rights as a research participant, you may contact:

University’s Research Ethics Officer,
Office for Research,
Bray Centre, Griffith University,
Kessels Road, Nathan, Qld. 4111
Ph: 07 3875 7111

Griffith University gratefully acknowledges the support you have provided to its research initiatives.
APPENDIX G

GRIFFITH UNIVERSITY

STUDY INFORMATION SHEET

HEALTH PROFESSIONAL

Chief Investigator:  Associate Professor Marianne Wallis RN PhD
School of Nursing and Health
Gold Coast Campus
Ph:  07 5552 8728

Co-Investigators:  Carole Anderson RN PhD Candidate
School of Nursing and Health
Gold Coast Campus
Ph: Free Call  1800 90 5900 Pin No: 9782

Dr. Winsome St.John RN PhD
School of Nursing and Health
Gold Coast Campus
Ph:  07 5552 8935

Project Title:  Implantation of a person’s heart with a permanent
bio-electronic device: A phenomenological study.

The purpose of this study is to understand the experience of implantation of the body
and the heart with an implantable cardioverter defibrillator (ICD).

You are being asked to participate in a research study because you are a health
professional who has recent cardiac care experience with recipients of ICDs. The study
is part of the doctoral program of one of the investigators, Carole Anderson, who is an
experienced cardiac nurse. You are invited to read this form carefully and ask Ms
Anderson any questions that you may have before making a decision whether or not to
participate. This form contains important information and telephone numbers, and you
will be given a copy to refer to as the study proceeds.

The study will consist of in-depth conversational style interviews with Ms Anderson at
a venue of your choice and at your convenience. Telephone interviews are also an
option. You will be asked questions about your experience with ICD implantation, your
experience with recipients of ICDs and their family members, how you feel about the
device, any problems or issues you may have with the device, and any solutions you
might suggest related to your professional experience with implantation of the person’s
heart. There will be two interviews each lasting more or less than an hour with several
weeks between interviews. The interviews will be audiotape recorded with your
permission and Ms Anderson will be taking brief notes. Most questions will be open-ended allowing you to tell your own experience. Ms Anderson will be discussing with you summaries of previous interviews at subsequent interviews so that you can clarify or confirm the accuracy of her understanding of those discussions. In addition, if you wish, you may read and discuss the transcripts of your interviews with Ms Anderson. Feedback in the form of a summary will be provided to you at the end of the study.

It is expected that there will be no physical risk from your participation in this study. You have the right to end any conversation at any time. You may gain no direct benefit from the study. However, you may find participation in this study validating. Knowledge about the experience of living with an ICD implanted within the body and heart will be used to inform health professionals and to improve the quality of health care.

Every effort will be made to maintain confidentiality. The results of this research study will be presented at meetings and in publication; however, descriptions of your identity and location will not be disclosed. All interview forms, audiotapes and transcriptions from the interviews will contain a pseudonym and this information will be locked away.

Participation in this study is voluntary. Prior to each interview, there will be an opportunity for you to ask questions about your continued participation in this study. You are free not to participate or to withdraw at any time, for whatever reason. You may withdraw from the study at any time without having any affect on your profession. In the event that you do withdraw from this study, the information you have already provided will be kept in a confidential manner.

For more information concerning this research you are free to contact the Chief Investigator Associate Professor Marianne Wallis on 07 5552 8728. If you have concerns, please contact Ms Anderson. If you have any questions about your rights as a research participant, you may contact:

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Bray Centre, Griffith University,
Kessels Road, Nathan, Qld. 4111
Ph: 07 3875 7111

Griffith University gratefully acknowledges the support you have provided to its research initiatives.
Fire and Ice

Core of me
Beats diligently
Red life flows

Rhyme without reason

A river of resonance
Strong
Ambivalent
Quivering unpredictability

A floundering drum;
Swirls of emotion
Fraught with dampened fire

Wet with fear of intrusion
by
Metal ice pond

A guest of necessity
Sits inside
My private corner

Against my soul:
Threatening the spiritual bricks
Built over a life time

Encapsulating tender feeling,
Made to live forever
with
or

without
the bitter cold wind invasion

Metal ice surrenders
To that core of me that yields
my fire of
human individuality.
REFERENCES


Klein, M. (1999). “You be the husband and let me be the doctor.” In J.M. Borkan, S Reis, J.H. Medalie & D. Steinmetz (Eds.), *Patients and doctors*. Wisconsin: The University of Wisconsin Press.


