

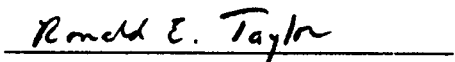
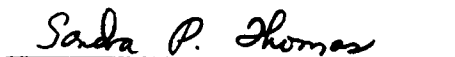
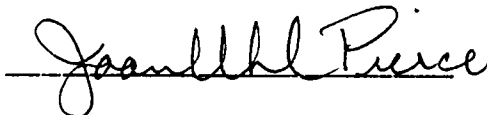
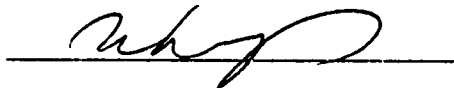
To the Graduate Council

I am submitting herewith a dissertation written by Stephen D. Krau entitled "An Existential-Phenomenological Study of Living with an AICD (Automatic Implantable Cardioverter Defibrillator)." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.



Inez Tuck, Major Professor

We have read this dissertation
and we recommend its acceptance:



Accepted for the Council:



Associate Vice Chancellor and
Dean of the Graduate School

AN EXISTENTIAL-PHENOMENOLOGICAL STUDY OF
LIVING WITH AN AICD
(AUTOMATIC IMPLANTABLE CARDIOVERTER DEFIBRILLATOR)

A Dissertation
Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Stephen D. Krau

August 1995

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DEDICATION

In celebration of the life of

Ivy Victoria Fountain Krau, RN

(1918-1994)

Mom and friend,

Who continues to care through the lives she touched.

ACKNOWLEDGEMENTS

I would like to acknowledge and thank the people with whom I cocreate and coconstitute a fascinating environment! I would like to express my appreciation to Dr. Inez Tuck, my dissertation committee chair who let me believe I could accomplish anything and whose guidance and knowledge made my dissertation process a pleasure. I would like to thank Dr. Sandra Thomas, a true friend and mentor who has illuminated many paths for me. I would also like to thank Dr. Joan Uhl-Pierce for her energetic and fresh perspective on my research and Dr. Ron Taylor for his expertise in qualitative research methods. I would like to thank Dr. Lee Humphreys, who, although is not from the South, is the personification of a true Southern gentleman and scholar.

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ABSTRACT

The automatic implantable cardioverter defibrillator (AICD) has been approved by the U.S. Food and Drug Administration as a treatment modality for persons with ventricular tachycardia since November 1985. Little is known about the impact of the device on the recipient's daily life. The purpose of this study is to uncover the impact that the device has on the recipient's day to day existence.

In order to answer the question: "What is the lived experience of people who have an AICD?" this study was conducted using an existential-phenomenological approach. Twelve recipients who have had the device at least six months were interviewed.

Data were analyzed using the Giorgi (1975, 1986) method of analysis. A situated structure for each subject is presented. Themes that emerged from the data were synthesized and abstracted into dimensions that form the general structure of living with an AICD. The context of the experience is the cardiac experience which is grounded in time. Dimensions of the experience are seen in the story of assimilation, an ongoing, dynamic process. The story of assimilation originates with the dimension of choice/no choice and contains dimensions of trust/absence of trust, understanding and support. A variety of syzygies related to trust and

understanding emerge as well as syzygies related to isolation and connectedness. From understanding, behaviors related to the physical presence of the device emerge. From the dimension of trust, actions of self-regulation appear. Metaphors related to the device and its action are presented, as well as descriptions of the actual "shock" experience in the subjects' own words.

The findings are discussed in relation to Parse's (1981, 1992, 1995) theory of human becoming. Implications for nursing interventions and further research are addressed.

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CHAPTER 1

Introduction

The automatic implantable cardioverter defibrillator (AICD) as a treatment modality for persons with ventricular dysrhythmias has been used for a relatively short period of time. Due to its recent development, most of what is known about the impact of the AICD on its recipients focuses on survival rates and the efficacy of the device. Little is known about the impact of the device on the lives of its recipients from the recipient's perspective.

Therefore, the purpose of this study is to provide a description of the lived experience of persons who have an AICD. In an effort to acquire an understanding of this experience, the aim of this research is to uncover the meaning that living with an AICD has for the AICD recipient. The results of the research will provide a deeper and fuller understanding of the impact of the AICD in the recipient's day to day existence.

Statement of the Problem

This study will use an existential-phenomenological approach for data collection and analysis. The purpose of this study is to answer the question, "What is the lived experience of people who have an AICD?"

Background

Cardiovascular disease is the leading cause of death in the United States as it accounts for roughly half the total mortality. The American Heart Association (1987) estimates that up to 1,000 cardiac arrests occur daily in the United States with 66% of the resulting deaths occurring before the patient reaches the hospital. Ventricular tachycardia, which often progresses to ventricular fibrillation, has been shown to be the dysrhythmia that occurs in 75% of the patients who experience sudden cardiac death (Deluna, Coumel, & Lederer, 1989). Sudden cardiac death is the standard nomenclature that indicates loss of consciousness due to a cardiac event that would lead to one's demise if resuscitation measures were not implemented. There is much evidence that indicates an acute myocardial infarction is usually not the precipitating event in sudden cardiac death, but rather that an occurrence of ventricular tachycardia or ventricular fibrillation precedes sudden cardiac death (Bremner, McCauley, & Axtell, 1993). Such findings have been the impetus for the development of means by which the provision of prehospital cardiac life support might be improved. One of the most recent tools developed in this endeavor is an internal cardiac defibrillator unit, known as the automatic implantable cardioverter-defibrillator.

Approved by the United States Department of the Food and Drug Administration in November of 1985, the AICD system continuously monitors cardiac activity. It senses ventricular tachycardia and ventricular fibrillation and aborts these dysrhythmias with countershocks of between 25 and 30 joules delivered through electrodes that have direct contact with the heart. The system consists of a pulse generator which contains the battery, capacitors and computer information, and the lead system which monitors heart rhythm and delivers the countershock. Through an operative procedure, the sensing and shocking leads are placed in and/or on the heart, and the pulse generator is implanted in a subcutaneous pocket in the left periumbilical area. A picture of the device and its placement is depicted in Appendix A, Figure 1.

Criteria for receiving an AICD are restrictive. Candidates for AICD placement should either be survivors of sudden cardiac death not associated with a recent myocardial infarction whose inducible arrhythmias at electrophysiology study cannot be controlled pharmacologically, or patients with more than one cardiac arrest whose arrhythmia cannot be induced at electrophysiology study (Cannom & Winkle, 1986). More recently, criteria have expanded to include persons with syncopal episodes not documented to be ventricular tachycardia or ventricular fibrillation, but in whom ventricular tachycardia or ventricular fibrillation is inducible during electrophysiology

study (Arato, Biggs, & Williams, 1992; Mason & McPherson, 1992). Studies are currently in progress to determine if AICD placement is warranted in high-risk patients as a prophylactic measure (Mason, & McPherson, 1992; Trouton, Powell, Garan & Ruskin, 1993; Wilber, Koop, Olshansky, Kall, & Kinder, 1993).

Sudden cardiac deaths are so low in patients who have the device implanted that a substantial treatment effect is easily inferred (Bigger, 1991; Fogoros, Elson, & Bonnet, 1990; Lessmeier et al., 1994; Qualey, 1989; Tchou et al., 1988; Winkle et al., 1989). Because there are no well controlled randomized studies, the current risk of recurrent sudden cardiac death in patients without AICDs is uncertain. More than 30,000 persons have had the device implanted (Davidson, VanRiper, Harper, & Wenk, 1994). In the United States alone, it is forecast that about 30,000 AICDs will be implanted in 1995 (Hammill & Stanton, 1995). This technology further diversifies the population of patients with cardiac disease, and the population as a whole, and is clearly a technology that is not transitory.

No systematic studies have attempted a comprehensive depiction of the lived experience of this population. There have been studies concerning anxiety and depression in this population (Keren, Aarons, & Velti, 1991), as well as anxiety and anger in this population (Vlay, Olson, Fricchione, &

Friedman, 1989), the economic and social impact of the device on its recipients and the health care system (Saksena & Camm, 1992; Vlay, 1986), the impact of the device on the recipients' quality of life (Cooper, Luceri, Thurer, & Myerburg, 1986), and the coping strategies this population uses (Kuiper & Nyamathi, 1991). Studies, for the most part, have been based on anecdotal information or have abbreviated the lived experiences of this population to a few attributes or concurrent psychiatric diagnoses.

Most nursing literature has focused on an explanation of the device, teaching, and physical care for persons who receive the device. Although the information is important, it centers on the physiologic importance of the device, and patient care essentially related to follow-up care and maintenance of the device. A holistic view of the impact of the device on the recipient is missing.

Nurses are in the position to help people gain understanding of their relationship with the environment to achieve optimum health. In order for this to be done, nurses must cultivate some understanding of the impact that AICDs have on the lives of this population. Understanding has been fragmented, as a the result of gaining information from externally designated and particularistic aspects of human experience. The fragmentation is a demonstration of a systematic misrepresentation of the character of the world

as lived, in that it describes characteristics of the population rather than the lived experience of the population. It is also antithetic to a nursing philosophy that posits a holistic view of humans as "an integration that does not allow one to know the individual by breaking the individual into parts and piecing them back together" (Munhall, 1989, p. 21).

To understand the human experience of living with an AICD, it is necessary to consider Husserl's (1970) appeal to "return to things themselves" (p. 252). One interpretation of that expression indicates that it is necessary to return to this population to reveal the lived experiences of this population in the everyday world in which the experiences are lived. It is the aim of the phenomenological approach to delineate experience as it is lived.

Knowledge for nursing can be acquired by using an existential-phenomenological approach to focus on human beings and their potentials as they experience their realities. Merleau-Ponty (1964) emphasizes that it is the perception of experience that matters, not what may appear more "truthful." Consequently, what is important from this world view is not what is actually happening, but rather what is perceived as happening by the individual. The experience as it is lived by the individual is the reality of concern.

Persons, when viewed through an existential-phenomenological perspective, are not viewed as objects in nature, but rather as an indissoluble

unity or in interrelationship in his or her world. In the purest sense, persons are viewed as having no existence apart from the world, and the world as having no existence apart from the person. In Merleau-Ponty's (1962) view, it is through one's body that one gains access and experiences the world. One sees, touches, thinks, and is conscious through the conditions the body offers. Nursing's concern for the person and the relevance occurrences have for an individual mandate the recognition that experience is individually perceived and interpreted.

As stated by Munhall (1989), "Nursing has advanced a philosophy that embraces the whole of the human condition. It professes values that include respect for each individual and their cultural interpretation of meaning in experience and events" (p. 27). With this in mind, an existential-phenomenological perspective becomes imperative for a research design, and ultimately for the actual delivery of holistic, empathic nursing care.

Significance for Nursing

Nurses focus on the patient and the interrelationships of health, illness, and disease as human experience. Nurses attend to the patient's story and the meaning that these factors have for the patient. As Benner and Wrubel (1989) affirm:

The best nursing practitioners understand the difference and relationships among health, illness and disease. This understanding leads nurses to seek the patient's story..., because they know that every illness has story - plans are threatened or thwarted, relationships are disturbed, and symptoms become laden with meaning depending on what else is happening in the person's life. Understanding the meaning of the illness can facilitate treatment and cure.... Understanding the meaning of the illness for the person's life is a form of healing, in that such understanding can overcome the sense of alienation, loss of self-understanding, and loss of social integration that accompany illness. (p. 9)

This study will attempt to uncover the meaning that living with an AICD has for its recipients and to gain understanding of experience of living with an AICD. Care provided by nurses to AICD recipients can be augmented by a thorough understanding of the experience of living with an AICD from the perspective of the person with an AICD. This knowledge can be of value to nurses as they provide informational support and an environment that is healing for the AICD recipient. Understanding the meaning of the experience of the recipient can assist nurses in preparing AICD candidates. This knowledge can strengthen the role of the nurse as a proponent of informed

consent for AICD candidates. Understanding the meaning of the experience for the recipient can abet nurses in preparing new AICD recipients as to what to expect after implantation. The information revealed may also yield aspects of living with an AICD that may be useful in the development of new nursing interventions designed to benefit AICD recipients.

Assumptions of the Researcher

The articulation of personal assumptions is a necessary prerequisite for a study of this type. Herein, the researcher articulates his beliefs about the research question. These assumptions incorporate personal knowledge about the question acquired from professional and informal contact with members of this population, and knowledge acquired through the literature review.

Human beings are the central focus of nursing's concern, and much of the origin of knowledge about human beings can be found in the everyday practical activities of individuals. Persons who experience similar events in a shared cultural and linguistic community, identify and articulate their experience in a comparable and consistent manner.

The experience of having an AICD is a personal and critical experience that begins with the intentional decision to have the device implanted. The choice to live with an AICD is a deliberate and self-initiated act of the person

with guidance from health care professionals. The experience of living with an AICD impacts the person's perception of self and the world as well as his or her encounters with the world. In order to support the person who has had the device implanted, the nurse must understand the meaning of the experience itself as understood and conveyed by the recipient.

The researcher has come into contact with persons with AICDs on a professional basis during acute cardiac events. It is after the cardiac event when the patient is stabilized and the fear of imminent death dissipates that questions about the AICD tend to emerge. Generally, it is also then that family members and the patient seem to feel free to talk about their experiences and concerns related to the AICD. It is apparent that because nursing staff in the hospital have an awareness and understanding of the device, that patients and family members in most cases are comfortable talking to nurses about the device. Some of the questions they ask, and some of the issues they raise are not well disclosed in nursing, or in medical literature.

Patients and their families appreciate talking to people who are knowledgeable about the device and numerous aspects about living with the device; knowledge that is essential if holistic care is a goal. Appreciation of others who know about the device is evident when people who have the device are hospitalized and these patients or their families meet. An immediate

rapport springs from the commonalities centering around the device. Family members and patients begin to compare and discuss their experiences. The experience of living with an AICD, or living with someone with an AICD provides an important bond. Understanding and knowing about the AICD is important, even in the face of other cardiac events. It is doubtlessly important for the nursing staff to know more about the living with the AICD from the patient's perspective. Understanding, in this researcher's professional experience, is an essential component to practice.

It is apparent that the foci of health care providers who recommend and implant the device, and care for patients with the device, have been on the efficiency of the device in preserving life. This is undoubtedly an essential consideration. For nursing professionals, where a holistic perspective is warranted, the heart and devices to enhance the functioning of the heart are an integral part of one's being.

The impact of technology on the human opens a new realm of nursing, medical, legal, and ethical considerations that have not been explored. It is only through understanding the impact of the technology on the human's existence that these new realms can be approached. For persons with AICDs this fundamental understanding can be obtained only from these persons as they come to understand and reveal what it is like living with the device.

CHAPTER 2

Review of the Literature

This chapter begins with a general review of the literature about AICDs and presents knowledge about persons with AICDs. Studies related to the impact of cardiac pacemakers and cardiac transplant on their recipients are also addressed. These modalities are similar to AICDs as technological processes designed to treat underlying cardiac problems. This chapter ends with a review of the literature related to the researcher's philosophical underpinnings.

Knowledge about the AICD

Much of the literature outside the nursing discipline about AICDs discusses the indications for the device, the efficacy of the device, a description of the device, and the operative procedure by which the device is implanted (Bigger, 1991; Cannom, 1992; Cannom & Winkle, 1986; Critelli & Yang, 1992; Edel, et al., 1991; Horowitz, 1992; Meesmann, 1992; Qualey, 1989). Robinson and Windle (1994) discuss ways to ameliorate the incidence of Twiddler's Syndrome, a syndrome more associated with pacemaker patients manifested by patient-induced rotation of the battery and its pocket resulting in lead disruption.

Nursing literature is appropriately concerned with assisting nurses in their endeavors to help AICD recipients manage and maintain their AICDs. Moser, Crawford, and Thomas (1993) provide one of the most recent and thorough presentations of the AICD in nursing literature. They discuss the indications for AICD implantation, nursing care for persons with an AICD, and describe the principles and operative conditions of the AICD. Their presentation is based on medical recommendations and is a reiteration of the medical focus of the device. The authors focus on the device and not the response of the patient to the device.

In the same fashion, Nichols and Wolverton (1991) focus on the teaching of persons with AICDs before they leave the hospital after the implant. They discuss outcome criteria that the patient must demonstrate before discharge. Specific outcome criteria are delineated and presented.

Literature regarding nursing outcomes and goals for persons with AICDs is abundant (Arato, Biggs, & Williams, 1992; Bower, 1994; Davidson, VanRiper, Harper, & Wenk, 1994; Harper & VanRiper, 1993; Mason & McPherson, 1992; McCrum, & Tyndall, 1992; Schaefer, Chicca, & Fisher, 1992; Veseth-Rogers, 1990). There are numerous nursing reviews about the technology of the AICD written to enhance nursing awareness of the device, and the means by which it works (Arteaga & Drew, 1991; Greatbatch, 1991;

Thomson & Olash, 1990). Fabiszewski and Volosin (1992) discuss the nurse's role when an AICD patient refuses to have the device's generator replaced.

Several issues and recommendation for persons with AICDs continue to surface in the literature. The issues surrounding driving and varying state legislations are presented by Larsen, et al. (1994) and Davidson, VanRiper, Harper, and Wenk (1994). Ethical issues concerning the removal, or discontinuance of the device for persons for whom death is imminent have emerged as recent concerns (Quill, Barold, & Sussman, 1994). As utilization of the device grows and conditions in recipients change as time passes, the discussion of the device as a lifesaving versus life-sustaining intervention will pose more legal, ethical and moral issues.

Knowledge about Persons with AICDs

Research studies targeted at psychological reactions to AICD implantation and or psychosocial adjustment have been limited. Studies primarily focus on one or two aspects of living with an AICD rather than looking at the lived experience in its totality.

Vlay (1986) investigated the economic and social impact of eight patients with AICDs. All resumed an active social life with 50% returning to their previous employment. He concluded that the social impact of the AICD

on the patient and the patient's family was positive. This conclusion was not based on patient report, but based on the fact that the patients were alive and active. Being alive and active was the measurement of positive impact.

Keren, Aarons, and Velti (1991) assessed anxiety and depression in patients with life-threatening ventricular arrhythmias. The authors compared scores on the Spielberger State Trait Anxiety Inventory (STAI) and the scores on the Beck Depression Inventory among three groups. Each of the three groups had six participants and two of the three groups consisted of persons with AICDs. One AICD group had experienced shocks from the device; the other had not. The third group consisted of persons with cardiac arrhythmias who did not have AICDs, but were medically treated for arrhythmias.

The study revealed no difference in the anxiety and depression scores among the three groups. A questionnaire designed by the researchers specifically for persons with AICDs revealed that the recipients had favorably accepted the AICD. No one in the sample who had not experienced a shock from the device would advise another patient against having the AICD implanted if confronted with the choice. Two in the group who had experienced shocks from the device reported that they would advise another patient against AICD implantation. Interestingly, if faced with the personal decision again to have the device implanted, none decided against

implantation. However, 5 of the 12 patients were not sure how they would decide. Only 3 of the 12 AICD recipients had felt that their general sense of well-being had improved as a result of the device. Two persons, one from each subgroup, reported a worsening sense of well-being since implantation.

Despite the scores on the Spielberger (STAI) that reflect no significant differences among the groups, 50% of the AICD recipients who had experienced shocks reported they were more anxious as a result of the AICD. This is certainly an indication that a different subjective understanding of anxiety was experienced in the patients than what was reflected in the standardized questions in the Spielberger STAI. That individual interpretations of what constitutes anxiety may vary, and are not necessarily the same as captured by the Spielberger STAI.

The study was designed to assess the presence of specific emotions in patients with AICDs, namely anxiety and depression, and to compare persons without the device to two categories of persons with the device. From the onset of the study, the scope of the experience of living with an AICD was limited to two emotional variables. The questionnaires designed to reflect the patients' experiences with an AICD were very focused, and directed toward illuminating the presence of anxiety and depression. The wholeness of the experience of living with an AICD was not the focus of the study.

Luderitz, Jung, Deister, Marneros and Manz (1993) used the State Trait Anxiety Inventory (STAI) and a specifically designed questionnaire to evaluate the impact of an AICD on quality of life, psychological profile, and patient acceptance of the device over a 12 month follow-up period. Fifty-seven patients comprised the sample in this study. The STAI was administered before implantation and at certain intervals (1, 3, 6, and 12 months) after implant. The questionnaire, consisting of eight questions designed to discover adjustment to the device, was completed by the patients after a long-term follow-up of about one year.

The results showed that 20 patients were afraid of AICD discharge; 12 patients indicated discomfort due to the device; and perceived quality of life was limited in 8 patients. Fifty-five of the 57 subjects stated it was worth having the device implanted; 30 patients reported returning to an active life; and all but one subject would advise another patient to undergo implantation if necessary. There was only a slight decrease in the level of anxiety within the total 57 subjects after AICD implantation. Age and number of shocks seemed to be factors that accounted for the variation in levels of anxiety, as younger patients had significantly higher anxiety than older patients. Persons who had experienced five or more shocks were more anxious.

The study addresses the uniqueness of the experience of living with an AICD, but limits the scope of the experience to acceptance of the device. This acceptance is determined by anxiety levels of recipients over time, as measured with the specific questionnaire. Although the information is important with numerous implications, it describes circumscribed characteristics of the group. These characteristics were hypothesized by the researchers to be important a priori, and then assessed. The study does not capture the experience of living with an AICD, only acceptance of the device and anxiety levels of the recipients. The study is certainly important and makes a valuable contribution to understanding this population, but yields only incomplete information.

Morris, Badger, Chmielewski, Berger and Goldberg (1991) examined psychiatric morbidity following implantation of the AICD in 20 recipients. Prior to implantation, the subjects were evaluated for baseline pre-existing psychiatric disorders. Psychiatric diagnoses were made using the criteria of the American Psychiatric Association's Diagnostic and Statistical Manual, 3rd Edition, Revised (1987). The sample was observed over a 3 to 21 month period after implantation. The prevalence of psychiatric disorder was 50%. The majority of these conditions were of a mild, transient nature and included transient adjustment disorders that were mixed, anxious, or depressive in type.

Six of the patients experienced transient adjustment disorders, three presented with major depression, and one was diagnosed with panic disorder. This prevalence was based on the development of psychiatric morbidity that was not detected pre-implant. These disorders were associated with psychological distress in family members, inadequate social support as perceived by the patient, and unplanned peri-operative AICD shocks. The study has pertinent implications regarding social support of AICD patients. It also illustrates psychiatric morbidity as a risk for AICD patients.

Cooper, Luceri, Thurer and Myerburg (1986) reported on the quality of life after implantation in 17 AICD patients. Psychological, social, and physical activity data were collected by interview. The interview technique involved open-ended questions concerning work history, physical, sexual and recreational activity; descriptions of the shock, and accompanying emotions, along with other areas of concerns that have resulted in adaptive lifestyle changes. The interview was guided totally by a specific scheme of questions, that did not allow the interview to be subject led. The purpose of the study was to describe problems persons with AICD encounter.

The patients primarily expressed a fear of shocks and indicated that a lack of warning that a shock was going to occur was more frightening than the shock itself. Decreased social and sexual activity were also seen in this group.

Lifestyle changes, the problematic size and position of the AICD, sleep disturbances, and concerns regarding body image were also revealed by these subjects.

The results of the study by Cooper, Luceri, Thurer and Myerburg (1986) are most closely related to the study presently proposed. The study demonstrates multiple physical, social, and psychological alterations that occur in this population. A strongly supported need for intensive patient education by nursing and medical staff is apparent. The study also demonstrates that having an implant is not a benign process and that information obtained from the patient's perspective of the lived experience is important.

Currier and Packa (1992) presented a case study of a 65-year-old female with an AICD. This case study focused primarily on the physiological indications for the device implantation. The authors utilized the Systems-in-Change Model to categorize the patient's problems once the device was inserted. The domains of the problems addressed included the biological, personal, and social system. In this particular case the personal system problems included an alteration in self-concept related to perceived dependence on the AICD, altered body image, and fear related to AICD malfunction. Social system problems focused on financial concerns related to the surgical procedure and follow-up, and self-care deficit related to lack of knowledge

about the device. All problems were identified by the nursing staff during the subject's post-operative period. Whether or not these problems were identified or even acknowledged by the subject is not clear.

Kuiper and Nyamathi (1991) investigated the stressors of and coping strategies used by patients living with an AICD. Utilizing a methodological triangulation design, the Jaloweic Coping Scale (JCS) and a semistructured interview guide were used to obtain data from 20 subjects. Mean scores on the JCS revealed that subjects scored highest on emotion focused coping styles, particularly the optimistic styles. Self-reliant coping was the next most frequently used type of emotion-focused coping, followed by problem-focused styles. The subjects in this study used primarily emotion-focused coping strategies and a mixture of other strategies to deal with the stress of living with an AICD.

The interviews revealed different coping strategies in the physical, psychological, and social realms. Patients used more problem-focused strategies to deal with the physical adjustments to stress; they used emotion-focused strategies used primarily to deal with psychologic, and social stress. Stressors identified and confirmed in the semistructured interviews were numerous. Sexual activity, concerns about the future, restrictions on physical activities, restricted social interactions, appearance and sleep disturbances,

changes in clothing, dependency, and thoughts of death were important concerns of the AICD patients. Stresses were also related to uncertainty of discharge and inadequate social support.

As the concepts in question were multidimensional, the design and method of inquiry were appropriate. The study examined areas of concerns of this population that can be targeted for intervention. It yielded valuable information about stressors and coping strategies used by this sample, which is undeniably important, but provided only a restrictive account of living with an AICD. As the exploration was directed by the JCS and the semistructured interview designed to determine stressors, other aspects of living with an AICD were missing.

Teplitz, Egenes, and Brask (1990) describe the development of a support group for persons who have experienced sudden death, and then become the recipients of an AICD. The researchers identify themes and concerns that have emerged from the support group sessions. The themes and concerns that they identify were derived from the lived experience of persons with AICDs. The authors have identified the following concerns and themes:

Fear regarding the unpredictability of the patient's dysrhythmia, resulting in a potential loss of consciousness in public; Concern about the experience of the first shock from a defibrillator; Spouse's fear of

receiving a shock during body contact with the recipient; Anxiety regarding the perceived body image changes as a result of an AICD; Driving restrictions interfering with the patient's feeling of freedom; Lack of general public knowledge about the AICD; Travel concerns; Perceived role reversal changes and a new life-style adaptation; Cost of the device and hospitalization; and Premature battery replacement and device failure. (p. 29)

It is important to note that these findings were not the result of rigorous scientific research, but rather impressions gathered by the authors as facilitators of the support group. It is also notable that the purpose of the group was to deal with concerns, fears, sharing of problems, and reduce anxiety. As a result, these themes are the reason that the support group exists. These themes warrant attention as they indicate certain aspects that are problematic in the lived experience of persons with an AICD, but should be regarded within the context and purpose of the support group.

Related Heart Transplant and Pacemaker Literature

Selected research literature discussing persons with heart transplants and cardiac pacemakers were reviewed for possible similarities to persons with AICDs. All are treatment modalities that have been the result of technologic

advances, and all have resulted in a wider array of patients with cardiac considerations. The three modalities involve interrupting the integrity of the body in order to introduce a foreign object to either augment or replace a heart that is compromised.

Much of the research dealing with heart transplantation focuses on the emotional aspects of the transplant and is found primarily in psychiatric literature. Lunde (1969), a psychiatric consultant to a cardiac transplant team, recounted his observations of situational psychiatric morbidity of heart transplant patients over a period of 18 months. Information was based on interview data and the author's evaluation of these data. The author concluded that complications requiring intervention by a psychiatrist are numerous and some, particularly depression and postoperative psychosis, have unique variations for transplant patients.

Kuhn, Meyers, Brennen, Davis, Lippman, Gray and Pool (1988) through examination of psychodiagnostic data in 69 heart transplant candidates, revealed that there was a high rate of anxiety and depression in heart transplant candidates. The authors used diagnoses as delineated by DSM-III (1980) third edition. These symptoms were related to the severity of the illness and the prospect of demise. They also found that the existence of

anxiety and depression do not predict adjustment difficulty or distress postoperatively.

Quality of life was examined in heart transplant patients by Packa (1989) utilizing the McMaster Health Index Questionnaire (MHIQ), which measures physical, emotional and social dimension of health, and the Cantril Self-Anchoring Scale. Packa (1989) reported that quality of life in each of the MHIQ dimensions was excellent with the highest rating in the area of physical functioning. Quality of life had improved significantly from the pre-transplant period in all of the subjects.

Most of the studies dealing with psychosocial aspects of persons with cardiac pacemakers took place 20 years ago. Greene and Moss (1969) studied the "adjustments with and adjustments to" pacemakers in 60 patients. Adjustments with and to pacemakers were based on the efficacy of the device in ameliorating cardiac symptoms and verbalizations of anxiety, anger and depression. Adjustment ratings were based on interviews of pacemaker patients in follow up visits with the authors. Adjustment ratings were based on consensus of the two authors. The study revealed that most patients make an excellent psychological adjustment to cardiac pacemakers with a rejuvenating lease on life. Ancillary good health, effective pacemaker function, and meaningful relationships provided the basis for good adjustment.

Blacher and Basch (1970) describe phases of adjustment to the pacemaker derived from their observations and interviews with 50 randomly selected patients who had permanent cardiac pacemakers. Themes emerged related to the adjustment including depression, loss of mastery, physical sensations, fantasies concerning the pacemaker and the feeling of being different. In essence, the study indicates that the patient views the device via his or her own fantasy as a mechanical-electrical machine or an artificial heart. The emotional aspects of the implanted device are well supported in this study.

Hesse (1975) describes a literature review that reveals that a substantial number of persons with permanent cardiac pacemakers experience difficulties adjusting to the device and to their medical condition. Hesse concluded that the difficulties often arise from the patient's misconception about the pacemaker and inadequate social support. The author recounts the development of the Pacemaker Social Support Program and observes a decline in the adjustment problems. This observation was based on the number of patients that sought formal psychological counseling after implantation of the device, and whether or not they were members of the established support group.

A questionnaire of 29 researcher-developed questions was used by Adorni, Benini, and Medici (1983) on 80 patients with implanted pacemakers

in order to explore psychological adjustments to the device. Results indicated that a favorable familiar environment and/or social environment is instrumental in helping pacemaker patients subdue their anxiety and "recompose good psychological equilibrium" (p. 117).

Summary

The literature reviewed is aimed at uncovering essential elements in the lives of those who have an AICD. It is clear that living with an AICD impacts various aspects of one's life and that the implantation of the device is not a benign treatment. Previous studies indicate that there is much to be revealed about living with an AICD.

Literature related to cardiac transplant patients and permanent cardiac pacemaker implant patients is sketchy, but supports the notion that more than just cardiac function changes as the result of these technological modalities. This literature adds to the merit of the study being proposed. To wit, it is clear that the technological procedures, though physiologically enhancing, are not innocuous. The extent to which these procedures and advances impact the lives of these patients is not known. An understanding of the impact of these devices on the day to day activities and thoughts of these patients is missing. The experience of living with an AICD has not been captured in its entirety.

A variety of emotions, concepts, and factors have been examined, but to date, no one has asked AICD recipients what it is like to live with an AICD.

Knowledge of the lived experience of this unique population is limited and fragmented at best. In order to understand this experience in persons with AICDs, it is necessary to go to persons with AICDs and ask them to tell about living with an AICD.

Philosophic Underpinnings

DeGroot (1988) maintains that convictions about the nature of human beings are essential to the development of the researcher's perspective. Other elements that are integral to the development of the researcher's perspective are beliefs about the nature of science, knowledge, and truth (Carper, 1978). These beliefs and values should be stated so that the position of the researcher can be appreciated.

Nursing, as a humanistic profession, maintains a basic philosophy that focuses on the individuality of persons, and the notion that the actions of individuals are in some sense autonomous. An individual makes choices, is self-determined, and is a dynamic, active being. Intrinsic to humanism are the philosophic beliefs and values that are found in nursing philosophies and often articulated in such language as human potential, becoming, freedom, self-

determination, autonomy, and advocacy (Munhall, 1982). The holistic view of the individual is well supported and posits that a human being possesses an integration that cannot be grasped by separating the individual into parts and piecing him or her back together (Munhall, 1989; Rogers, 1970). As persons are viewed as holistic, unique, and self-determined, it follows that each person experiences his or her own "reality." Even though the experience may be shared, it is the individual who interprets the experience and assigns its meaning. The person is typically not consciously aware of the interpretation of situations. Instead, daily activities are not reflected upon, and do not mandate interpretive attention (Wrubel, 1985, p. 45).

Husserl, who introduced the idea of phenomenology, did so in response to the context-free generalizations of the positivist approach of the natural sciences (Cohen, 1987; Spiegelberg, 1976). Phenomenology was Husserl's attempt to restore the "reality" of humans in their worlds and to capture the meaning of that this reality has for the individual. Spiegelberg (1976) explains, "Science itself was crying out for philosophy that would restore its contact with the deeper concerns of man" (p. 80).

Phenomenology has been considered to be a contribution of method applied to the phenomena of human consciousness. Existentialism, on the other hand, has been characterized by von Eckartsberg (1986) as:

...An effort to specify the essential and perennial themes of human existence in its broadest sense, as finite, embodied, mooded, in time, situated, threatened by death, capable of language, symbolism and reflection, striving for meanings and values and choices, self-fulfilling and self-transcending, as involving committing itself to relationships, accountable and capable of responsibility. Existential-phenomenology thus means the application of the phenomenological method to the perennial problems of human existence. (p. 8)

Existential-phenomenology, primarily associated with Heidegger, Sartre, and Merleau-Ponty, is an expansion of phenomenology as initially proposed by Husserl. Existential phenomenology recognizes the importance of the preconscious lived experience. It emphasizes that being in the world involves more than human consciousness and encompasses the total embodied human response to a perceived situation. Existence in this sense refers to "the concrete, biographical, and embodied life of named persons who are characterized by uniqueness and irreplaceability" (von Eckartsberg, 1986). Existential phenomenology examines existence in terms of the person's involvement in a situation within a world. The exclusive focus on experience, according to Husserl (1970), provides access to all that can be directly known, because all knowledge is ultimately grounded in human experience. There is

no viewpoint outside of the person by which to view things, as they do not exist independently of the person's experience of them.

Maurice Merleau-Ponty (1962, 1968), an advocate of the existential-phenomenological movement, primarily addresses the mystery that a person is a part of the world, and that the world is an extension of one's body. Body and world cannot be separated and are of the same nature. In the truest sense, the person is viewed as having no existence apart from the world, and the world as having no existence apart from the person. Each individual and his or her world are said to coconstitute one another. This is the primordial ground of all of our awareness, a kind of prolongation of our body that Merleau-Ponty metaphorically expresses as the "flesh of the world." Essentially, what one knows of the world, one experiences through one's body. Experiences of seeing, touching, and even understanding occur through one's body.

From this perspective, persons are always in the midst of the world and are not capable of a vantage point outside of it. As a result, total clarity cannot be achieved. Reflection and critical considerations according to Merleau-Ponty cannot totally permeate one's obscure primordial awareness in which significance is always already formed. This perspective differs from earlier ideas of phenomenology as it contains much more tentativeness,

ambiguity, and relativity than originally espoused by Husserl. This is the foundation for scientific inquiry, and for all science, objective as well as humanistic.

Merleau-Ponty (1962) suggests that a person's perception of an experience is what matters, not what may appear in reality to be contrary or more "truthful." The perception of the person is that person's lived experience. It is the interpretation of that experience that is critical. If danger is perceived by the individual, when "in fact" there may be none, in that person's reality, there is danger. What is essential in this perspective is not what is actually happening, but rather what the individual perceives is happening.

These ideas form the basis of several assumptions about the existential-phenomenological approach. One assumption that should be clarified is that existential-phenomenology rejects the notion of causality in its linear, or additive form. This mandates that the individual must be examined without proposing or testing cause-effect relationships. The notions of cause and effect relationships are irrelevant, as they have no place in explaining the lived world. As the person and his or her world coconstitute one another, events in one realm cannot cause events in the other. At best, one might discern sequences of behavior, but this in and of itself does not establish causality.

The existential-phenomenological approach proceeds on the assumption that identically named experience refers basically to a common reality in various subjects. Van Kaam (1969) indicates that people in a shared cultural and linguistic community, name and identify their existence in a consistent and somewhat shared manner. This coupled with Merleau-Ponty's ideas lead to the assumption that the existential-phenomenological approach is not objective or positivistic in nature, nor is it totally subjective.

The purpose of existential-phenomenology is to seek understanding of phenomena in their perceived immediacy as lived. It is not concerned with explaining, predicting, or controlling phenomena. As a result, description through disciplined reflection replaces experiment as method, and structure replaces cause-effect relationships as the content.

Structure according to Valle and Halling (1989) is a basic fundamental concept in existential-phenomenology. Phenomena as presented seem to show themselves in a variety of ways, depending upon how they are viewed at a given time, and depending upon variations in perspectives and situations. Regardless of the phenomenon's particular variation at any point in time, this phenomenon has the same essential meaning when it is perceived over time in various situations. Only after examining the phenomenon repeatedly from different perspectives, does the essence, form, or structure of the phenomenon

become known. The essential structure of a phenomenon is made up of the elements or constituents that are necessary for an experience to present itself as what it is.

Valle and Halling (1989) indicate that phenomenological philosophers are primarily concerned with "providing descriptions of the universal structure processes of consciousness" (p. 51). That is to say that they are concerned with structures that compose a common appearance and similarities in each person's experience. Although the specific experiences of human beings vary according to culture and personality, it is assumed that experience appears to have a primary and basic common structure.

As indicated by Giorgi (1975), there is always a risk when one applies concepts from a not-fully developed philosophy to arenas and situations outside the context of their philosophical development. Existential-phenomenology is by no means conclusive. When one sees phenomena that are worthy of being examined, but are not because of philosophical biases, popular theoretical perspectives, or lack of adequate methodology, a possibility for developing or opening new vistas for research makes the risk worth taking.

Nursing has promoted an ideology that embraces the wholeness of the human condition. It affirms values that include individual respect for each person and his or her interpretation of meaning in lived experiences. It also

espouses self-determination and autonomy of the individual. In so doing, an existential-phenomenological approach to investigating the lived experience of persons with AICDs is essential, not only as a research design, but also for the development of holistic and empathic nursing care. When asked, "What is it like living with an AICD?", an open, exploratory, theory-suspended approach is implied. An approach is selected that actualizes the conviction that the individual interprets his or her own experiences and gives meaning to those experiences.

CHAPTER 3

Method

An existential-phenomenological study was conducted to examine the experience of living with an AICD. The design and method are addressed, specifically the phenomenological method, and the method of data analysis as presented by Giorgi (1975, 1986). Discussion of the sample and setting will be followed by a discussion of rigor of the study. The chapter concludes with a discussion of the protection of human rights.

Principles of Phenomenological Method

In maintaining a method of phenomenology that is consistent with the philosophical tenets presented, there are certain principles that should be explicated. The first of these as presented by Munhall and Oiler (1986) is attentiveness to the subjects' realities in formulating the research question. The question centers on the lived experiences which is a fundamental principle related to the purpose of the study.

The second principle mandates that the researcher approach these realities in a holistic manner. This is done by going to the persons in their circumstances as they are involved in the world.

The third principle maintains that the researcher is immersed in the phenomenon of study because the researcher is studying it. This principle has implications for data-collection procedures. It also commands that there be some control over the researcher's involvement to minimize bias that would reduce the method to ordinary subjectivity in the empiricist sense. Yet it is important to consider Benner's (1994) views as she points out:

No claims can be made that the other will be understood completely because human beings and worlds are not objects and cannot be frozen in time or explicated fully. Furthermore, the interpreter can never escape his or her own taken-for-granted background or stance that creates the possibility of an interpretive foreground. (p. 17)

Due to the nature of the study, unobtrusiveness is impossible and not desired. The posture of the researcher in interaction with the subjects is further addressed by Giorgi.

Giorgi (1975) indicates that a bracketing procedure is necessary prior to the beginning of the study. This is important in the analysis of the data.

According to Giorgi (1975) in phenomenological research:

...the chief point to be remembered in this type of research is not so much whether another position with respect to the data could be adopted (this point is granted beforehand), but whether a reader,

adopting the same viewpoint as the researcher, can also see what the researcher saw whether or not he agrees with it. That is a key criterion for qualitative research. (p. 96)

Fidelity to the phenomenon as it is lived, as conveyed by Giorgi (1975), does not mean that the totality of the phenomenon can be captured in every conceivable aspect, as this is impossible. Rather it mandates that these aspects are apprehended and understood within the lived context of the one who experiences the situation, and that those aspects are perceived and understood by the researcher. Therefore the researcher must consider anything the subject deems worth mentioning as data. The researcher must also make explicit his or her viewpoint, biases, or personal assumptions. This embodies the rationale for the selection of this research design in the first place.

As the question under study focuses on the lived experience of AICD patients, the primacy of the life-world is essential. The primacy of the life-world as discussed by Giorgi (1975) is the grounds for all science and systematic knowledge. The notion of primacy guides the researcher to stay in touch with the sources of data, and requires dialogue between scientific expressions and the ordinary expressions of the life-world by participants. This necessitates that the actual words of the participants be moved up a level of abstraction. This involves the researcher taking the participants words, or

naive descriptions of the experience and interpreting or expounding on those words from the researcher's disciplinary perspective.

As phenomenology depends almost exclusively on the power of language for communication, symbolic description is its main technique. As Giorgi (1975) declares, "Language is the major means of communication in everyday life and phenomenology tries to make more rigorous the universal means of exchange by circumscribing attitudes, delineating aims, and providing adequate contexts for all descriptions," (p. 100).

Expression of the viewpoint of the subject is another element proposed by Giorgi as a characteristic of phenomenology. As the subjects are encouraged to discuss living with an AICD, in open-ended interviews, this element is preserved. After all, it is the subject's viewpoint of the situation that provides the data. This is clearly supported by Munhall (1994) who declares, "Perception of the experience is what matters, not what in reality may appear to be contrary or more truthful." (p. 15)

Giorgi (1975) states that the "lived situation is the basic unit of research," (p. 100). This embodies the idea that the primary variables are not defined physically, and that the significant factors are the meanings ascribed in that situation by the subject, and the researcher. This provides allowances for interpretation, as meanings are not always known explicitly, but must be

discovered or thematized. This does not undermine the research, but rather provides an acceptable limit as long as the context of the interpretations are made clear. It should be kept in mind that no factor that emerges in research can ever be considered independently of the total context of the study, regardless of the method.

In phenomenology, the researcher is engaged. This requires that the initial descriptions given by the research subject in an open-ended situation are transferred in dialogue with the subject toward the aims of the research. This engagement continues throughout the study. Benner (1994) embraces this notion as she suggests, "The interpreter moves back and forth between the foreground and background, between situations, and between the practical worlds of the participants." (p. 100).

Much scientific research searches for a method of measuring a phenomenon and then tries to evaluate the meaning and significance of the measurement. In phenomenology, the meaning *is* the measurement. As explained by Giorgi (1975, 1986), the phenomenologist gets directly to the meaning of the phenomenon by a method that systematically explores meaning without going through a measurement process in the strict sense of the term. A value of the phenomenological approach is its direct access to meaning by interrogating the qualitative aspects of the phenomena. To interrogate a

phenomenon for its meaning is an important aspect of nursing research that sanctions further development.

Data Gathering

A phenomenological study usually relies on data gathering to collect naive descriptions of the experience under investigation, or descriptions rendered by the participants that are initially only interpreted by the participant. It is these descriptions that provide specific instances from which the researcher can ascertain the structure of consciousness that constitutes the experience. As subjects are chosen who are able to function as informants by providing descriptions of the experience, this study dictates that persons who have been implanted with an AICD be chosen. In order not to contaminate the experience of living with an AICD with the operative and immediate post-operative experience, it is logical that subjects be persons who have had the device for at least six months.

There is much discussion about other criteria for subjects in phenomenological studies (van Kaam, 1969; Valle & Halling, 1989). Colaizzi (1978), whose method is closely related to Giorgi's, states that "Experience with the investigated topic and articulateness suffice as criteria for selecting

subjects," (p. 58). More recent phenomenologists have added the notion of 'readiness' to this criteria. As Munhall (1994) points out:

While there may be no apparent issue of coercion or expectations, individuals often genuinely wish to be helpful or even feel obligated to consent to an interview without realizing it is not in their best interest. As a researcher, you need to ascertain whether a person is ready emotionally and psychologically for an interview or conversation about his or her experience. (p. 93)

The Sample

The sample for this study is a mixed purposive sample of 12 people who have an AICD. Participants for this study were obtained through two AICD support groups. The nurse who coordinates one of the support groups asked members if any one would like to participate in the study. Volunteers provided their names, addresses and phone numbers on a roster that was circulated. The researcher received a membership directory from another support group in a hospital over two hundred miles from the first support group. Support group members in the directory had given consent to the hospital to have their names and addresses in the directory. The researcher randomly selected 20 men and women from the support group, and sent a

letter with a post card for response. The letter explained the study in detail; the postcard asked that the person check an affirmative or negative response and return the postcard. Of the 20 postcards sent, 18 were returned. Fifteen of those indicated they were willing to be interviewed. The directory had been published for almost six months prior to the first interview from this group. This assured that persons listed in the directory had been implanted at least six months prior to being interviewed.

All persons interviewed had the device more than six months, and all had received at least one post hospital-shock prior to the interview, although the shock experience was not a basis for selection. Readiness to participate was assessed from the initial phone call to arrange the interview, and throughout the interview. All participants were indicated that they wanted to discuss their experiences of living with an AICD. The sample consisted of persons living within a radius of 275 miles in rural and urban areas in three different states in the Southeastern United States. The sample consisted of eight men and four women. Eleven participants were Caucasian, and one was African-American. Five participants were employed outside of their homes. One participant had a shop in his home and still worked. Six of the participants were retired or unemployed. Additional demographic data on the participants is presented in Chapter 4, as the situated structure for each

participant emerges. Not all participants actually attended the support group meetings on a regular basis, as the support group meeting were every three months. Some participants had never attended a support group meeting although their names were on the roster.

Although 15 people indicated that they were willing to be interviewed, this study reached closure with theoretical saturation. This occurs when no new themes emerge in the interviews. Theoretical saturation was close, but not certain after the interview with the tenth participant. To assure saturation an eleventh participant was interviewed. The interview with the eleventh participant yielded very different data due to his experience of a device malfunction. Theoretical saturation was achieved in the twelfth interview where themes that could be identified in earlier interviews.

The Interview Procedure

All interviews were preceded with an explanation of the study, and an assessment of the participant's understanding of the study, and the signing of a consent form (Appendix B). Participants were given a copy of the consent form with special instruction about where the researcher could be contacted if the participant should decide later that he or she did not want remain in the study. This information was reiterated at the end of each interview. Research

participants were interviewed individually for 45 minutes to an hour and a half at a location of their choice. All interviews took place either in the participant's home, or at the participant's workplace after hours.

The interview focused directly on the experience of living with an AICD. The interview began with an unstructured open-ended request to describe the experience of living with an AICD. This request is consistent with Benner's (1994) notion of the qualitative interview, which is a narrative account that is meaningful to the point that it reveals what is perceived, what is worth attention, and what is a concern to the participant. A list of prompt questions was prepared by the researcher (Appendix C) to assist in the flow of the interview as needed. The first three participants addressed the prompt questions in their narratives before being asked. The prompt questions were not used after the third interview, and the interviews were totally led by the subject after the general question was asked. Two final questions were asked of each subject at the completion of the interview. One question was a hypothetical situation of another who is deciding whether or not to have an AICD, and the other was a question to see if there was anything else the subject wished to add, or had not covered in the interview. These final questions are the last two questions in Appendix C.

Interviews were audiotaped and then transcribed verbatim by the researcher. Each participant was assigned a pseudonym in the order of the interview, such that Abe through Lee represent participant one through participant twelve. This assured the anonymity of the participant and provided a humanistic, personal approach to identifying the participants. It is also eliminated awkwardness in identifying the participants.

Data Analysis

Giorgi's phenomenological method developed from a psychological background. Psychological phenomenological research usually does not focus on universal structures, but examines the level of structures that constitute psychological meanings in particular contexts or situations. Although a psychological perspective tones the method, the universal structures that emerge in living with an AICD have implications for nursing in teaching candidates for the device, for dealing with AICD recipients, and perhaps for identifying aspects of the lived experience that could lead to the development of effective nursing interventions. For this reason, the researcher developed a situated structure of the experience of living with an AICD for each participant as well as a general structure of the experience.

Giorgi (1975, 1986) describes the steps he utilized to analyze a protocol. This constitutes the technique that was used for the analysis of data obtained from persons with AICDs.

The first step in Giorgi's method of analysis is to read through the protocol to get a sense of the whole. This is done with maximum openness without direction from the specific aim of the research or the researcher's biases. The researcher transcribed the interviews verbatim, validated all transcriptions with the audiotapes, and reviewed the transcripts several times to get a sense of the whole.

The researcher then read through the protocol again and divided the transcript into unit blocks that seem to express a self-contained meaning. This was accomplished by noting each time a transition in meaning was perceived, such as a change in subject matter or a change in activities that were being described. This step required the researcher's judgement. Although this researcher read from a nursing perspective, care at this point was taken to treat the text as naive, and to seek divisions that occurred through the subject's perspective as narrated. In other words, the divisions were those imposed upon by the text rather than the researcher's perspective. Giorgi (1975, 1986) refers to these blocks as "meaning units" that should be considered constituents of the experience, as opposed to elements of the experience. These meaning

units maintain their identity as contextual parts of the experience. They are inseparable parts of the whole.

The third step (Giorgi 1975, 1986) utilized was a restatement by the researcher, as simply as possible, of the meaning that dominates the units. This removes the description of the experience from the participant's own words, which mandates some interpretation. This concise description of the meaning unit was the first transformation of the data from the subject's naive description to the researcher's words. These transformations were stated in third person. At this point, the analysis produced a division of the protocol into units that are accompanied by the statement of the situational theme in the words of the researcher.

The researcher then worked with the meaning units established in the second step and the transformations discussed in the third step. The question of the study, "What is the lived experience of persons with AICDs?", was asked of each unit and its accompanying transformation. This resulted in a second transformation in which the researcher drew out from each unit of the protocol those aspects that are related to the topic under investigation. Redundancies and units not related to the research question were eliminated. For example, in several interviews, participants would describe the mechanics of the device, their medicine regimens, or talk about the experiences of others.

These units were eliminated. When units were related to the research question and not redundant they were transformed in this step. The transformations in this step were identified as themes. Giorgi (1986) identifies this process as making "thematic the subjects' perceptions and intentions," (p. 18). The thematic perceptions and intentions at this stage are presented and are essential in demonstrating the evolution of a description for each participant.

An example of a meaning unit as identified in the second step, and a theme as explained as a transformation of the meaning unit is presented in Table 1. This meaning unit is germane to the study. The example comes from the interview with Abe.

Table 1. Transformation of subject's expressions into thematic perceptions

One Meaning Unit	One Theme
You can tell more or less when everything gets out of whack. The ole' head starts pounding, you know, where you can feel your heart beating in your head, and you hear it more in your ears. Ah! I don't pay it any mind anymore. You're always , when it goes off the first time, you're expecting another shock. If it don't come, it's a relief. But usually it takes about five minutes after you get your jolt to wait for everything to settle down. Because it, well, it just kind of upsets your whole system I guess you'd say. But you can just set down and in four or five minutes go on about your business.	Abe perceives that his body experiences disequilibrium and is aware of a change. The shock reorders what has become disordered, and although there is anxiety in anticipating the next shock, when it does not come, Abe experiences calmness. The shock reorders for Abe what has become disordered.

In this study, quotes from each participant's naive description are presented to demonstrate the meaning units, and to demonstrate the derivation of the themes. Once the meaning units had been transformed into themes, the researcher synthesized and tied them together in a descriptive statement of essential meanings. This resulted in the development of a situated structure of the phenomenon, which is a description of the lived experience for that situation or that particular participant.

Only after completing the situated descriptions did the researcher develop a description at the general level from the protocol. The construction of the general structural description left out particulars reported in the protocol, and centers on those aspects of the experience included in the protocol that are trans-situational or reflective of the narrators' lived experiences in general.

Giorgi (1975, 1986) allows, but does not impose a sole analyzer of the data. This researcher was the primary analyzer of the data, but solicited assistance from two qualitative research groups. One group analyzed the interview with Abe in its entirety and most of Bob's interview. Another group was instrumental in determining the auditability of the study. The second group verified the logic in the decisions of the researcher, which is a key criterion of any qualitative research according to Giorgi (1975, 1986). It is

important to note that the primary analyzer adopted the phenomenological philosophy of Merleau-Ponty. This means that descriptions provided by the subjects were read as much as possible without presupposition, and thematized from the subjects' viewpoints as understood by the researcher. Again, it should be reiterated that this perspective does not vitiate the findings, but rather defines the limits of the context in which they are valid.

Standards for Evaluation

To enhance the reported rigor of the study particularly for the nursing discipline, a discussion of rigor in qualitative research proposed by Sandelowski (1986, 1993) and Lincoln and Guba (1981) as it relates to this study is warranted. Four criteria appropriate for assessment of rigor in qualitative research include: (a) credibility, (b) fittingness, (c) auditability, and (d) confirmability. Each of these criteria will be described as it relates to this study.

Credibility was established in this study by use of "prolonged engagement" and "member checks" (Lincoln & Guba, 1985, p. 301). Prolonged engagement indicates that the researcher has an understanding of the subject and develops a trusting relationship with participants so that they will feel free to disclose information. All data collection in this study was gathered

by the principle investigator who has been a nurse for 15 years, who is comfortable and accustomed to establishing immediate rapport and asking sensitive questions, and who has worked with patients with AICDs for 4 years. Participants were not acquaintances of the investigator, nor had they been patients of the investigator. The researcher clearly indicated no affiliation with the agencies sponsoring the support groups, and assured confidentiality. Data collection took place over a 9 month period.

Member checking was another method used to establish credibility in this study. Certain participants were requested to verify the credibility of the interpretation of findings throughout the process of analysis. As the researcher is also in clinical situations with persons with AICDs who were not a part of the study, the researcher would ask about specific experiences of living with an AICD. In both settings for example, the investigator would say after the interview, "It seems some people with AICDs have experienced....Is it that way with you?"

Sandelowski (1986) suggests that a major threat to the credibility of qualitative research is that the researcher may "go native." This notion refers to situations where the investigator has such a close relationship with the participants that the investigator cannot divide his or her own experience from that of the participant. The researcher, who does not have an AICD, or any

cardiac problems, kept a journal noting ideas, feelings, impressions and behaviors in an attempt to keep from "going native."

Fittingness is the criterion that is used to appraise applicability in qualitative research (Lincoln & Guba, 1985; Sandelowski, 1986). Fittingness is identified when the findings are substantial and applicable, and fit into contexts outside of the study situation. Fittingness for this study was determined by re-examination of the literature cited in the literature review, and literature related to quality of life, language, and nursing theories to ascertain applicability in these contexts. Applicability to nursing theory, particularly Parse's (1981, 1992, 1995) human becoming theory (formerly man-living-health) provides an excellent framework for the discussion of findings and is presented in Chapter 5.

One of the major threats to fittingness includes "elite bias," which becomes a concern when a sample is chosen from an elite group. Elite bias was intentionally minimized by selecting participants from different geographical areas and different genders. Elite bias is further minimized by varying socio-economic statuses, employment statuses, length of time with the device, and diverse racial representation.

Auditability, according to Sandelowski (1986), "is achieved when the researcher leaves a clear decision trail concerning the study from its beginning

to its end," (p. 34). This is Giorgi's (1975) key criterion for qualitative research. The researcher documented the progression of decisions and interpretation used at each juncture in this study. To enhance auditability, for future readers, quotes from the participants were utilized to explain findings. The findings and decision trail, along with the raw data, were presented to a group of nurse researchers for verification that the decision trail was logical and appropriate. This was a different group from the group that assisted in the analysis of the first two descriptions. This is important to note as the first group consisted of persons from multiple disciplines, and was led by a psychological phenomenologist. The group supporting the "decision trail" were nurse researchers, with a perspective presumably similar to that of the primary investigator.

With regard to this discussion, it is essential to cite Giorgi (1986), who clarifies:

It is important to note that we are not saying that the meaning units exist in the text as such. They exist only in relation to the attitude and set of the researcher. For example, if one were to do a grammatical analysis of the description, one would look at the text differently than if one were to do a stylistic analysis....What stands out depends very much on the researcher's perspective. (p. 15)

Confirmability was achieved when the findings met the criteria of credibility, fittingness, and auditability. Credibility was enhanced by audiotaping and the transcribing the interviews verbatim. Two interviews were analyzed, coded and discussed in an interdisciplinary phenomenological research group which was led by a renowned psychological phenomenologist. Consensus in interpretation of the interviews was achieved. Data and findings were later reviewed by a nursing research group, so that differences in interpretation that may have habituated the researcher were discussed.

Human Rights/Subjects

Approval for the study was obtained from the Institutional Review Board of the University of Tennessee, Knoxville. Approval to ask for participants was granted by persons who are facilitators of AICD support groups in two locations. One location circulated a roster for volunteers once the study had been explained. A membership roster from another group was obtained, and participants were contacted by mail. All persons in the membership roster had signed consent to have their names printed. Twenty letters were sent with an explanation of the project and stamped postcards to be mailed for acceptance or refusal to participate. Eighteen of the postcards were returned, and 15 agreed to participate.

The principle investigator contacted the willing participants by phone to assure willingness and readiness, as well as to set up a time and place most convenient for the participant to be interviewed. Imminent to the decided time and place, the principle investigator confirmed the appointment and the participant's willingness to be interviewed. Prior to the interview, an explanation of the study was reiterated. The consent form (Appendix B) was reviewed and signed by each participant. A copy of the consent form was given to each participant with the means of contacting the investigator should the participant decide to withdraw from the study. Informed consent forms will be kept in a locked file in the home of the project director for three years upon completion of the study. None of the subjects interviewed asked to be withdrawn from the study.

As the primary investigator transcribed the interviews verbatim, assigning a pseudonym to each participant, all names mentioned in the interviews were deleted, and all participants were identified by the assigned pseudonym. Transcripts and audiotapes were kept in a locked file in the home of the primary investigator. Audiotapes were destroyed upon completion of dissertation approval.

Transcripts that were reviewed totally or in part by research groups to assure rigor of the research and assist in analysis were done so only after

members of these groups signed confidentiality agreements (Appendix D).

Review of transcripts was done only in the presence of the project director, or co-director.

CHAPTER 4

Analysis

The purpose of this study is to describe phenomenologically the experience of living with an AICD. For this study twelve persons who have had an AICD for at least six months were interviewed. Interviews were open interviews, with a set of questions that were used as prompts (Appendix C). The interviews were conducted over a period of nine months. The shortest interview was 45 minutes, and the longest interview was an hour and 35 minutes. Most interviews were close to an hour and fifteen minutes. Each participant signed a consent form (Appendix B) and each interview was audio taped.

The researcher assigned a pseudonym to each participant. Gender is evident through the choice of names. In order to give the protocol a holistic perspective, each participant is called by a name from A to L in the order of interview. This is not only to make the transcriptions more personal, but also to eliminate awkwardness in identifying participants and data.

This chapter includes demographic data about the participants as each case is presented. It also presents the constituents of the description of living with an AICD with support from quotations by the participants.

Analysis of Protocols

Abe

Abe is a 64-year-old male. At the time of the interview, his AICD had been implanted for three years and four months. Since his implant, he has experienced 35 shocks, the last one being six months prior to the interview. Abe has a 23 year history of cardiac problems that include three myocardial infarctions and by-pass surgery. After having failed drug trials to control his dysrhythmias and an event of sudden death, his physicians determined he would benefit by implantation of an AICD. Abe lives in a very rural town with his wife. He is a former garage mechanic and has been retired for seven years.

During the interview Abe conveyed that there is a process of acceptance of the device that takes place over time. He indicates that there is initially a great deal of anxiety surrounding the device. He warns, "If a person don't watch his self, he'll have anxieties. Some little something, he'll have a gas or something like that, and he would, I would say, have anxiety pains more than anything else. That was my problem to start with. I would catch myself just real tense, just waiting for the thing to go off." He indicates that it took a while to "relax and go on with life." He relates that his anxiety

surrounding the first shock was the worst, and that once he experienced his first shock his anxiety "wasn't bad at all."

Abe's perception of the device is very mechanistic. He refers to the device as being "installed" and suggests that the implantation process has become like "replacing a toenail." Abe is prescriptive in his description of the device as he likens it to a "good laxative." The device also serves in a regulatory capacity. Abe indicates that he does not "get out and push it," and when he gets a little hot or tired, he stops what he is doing. Abe uses metaphors and analogies when talking about the device. He refers to the device as an "electronic guardian angel," sometimes as "the silly thing," and he analogizes the device to "good laxative."

There is some ambivalence in Abe's engagement of activities. He relates that he does what he wants to do: "vacation, go to ball games, St. Louis, all that good stuff. Go fishing." But he warns, "Don't get out by yourself, I mean way out." So while the device provides a sense of freedom for Abe, it also restricts his activity since there's "always that possibility that something could go wrong." Abe drives short distances, but his wife drives long distances. The device allows him freedom for activities, but limits the margin of separation from others.

Abe is most aware of the device on a day to day basis when he goes outside and works in his yard. Since the battery of the device is at his waist line, when he gardens Abe says, "You can stoop over and it'll pop off your belt or something, and you get a good kick out of that." He also reports that he cannot lay on his left side to sleep because that makes the area "sore."

Abe describes the shock experience as a "young mule kick," but a meaning surrounding the shock is conveyed. He describes the shock experience as something "to get everything back into order", such that his body that has gone into disorder comes back into equilibrium with the shock. Prior to the shock, Abe reveals that "You can moreless tell everything gets out of whack. The ole' head starts pounding, you know, where you can feel your heart beating in your head, and you hear it in your ears." He goes on to say that "Usually it takes you about five minutes after you get your jolt to wait for everything to settle down."

He indicates that after a shock he anticipates another shock, yet senses relief in knowing that the device is "doing its job." There is a mixture of discomfort from the shock, apprehension in waiting for the next shock, yet relief that the device is functioning.

Abe relies on his trust in others. While he has not experienced many things that could happen with the device, he believes what he has been told.

For example, Abe has confidence in the device's warning beeper although he has never heard it. He states, "but they say it's there." His knowledge about the device turning itself off in a magnetic field is also the result of medical instruction and not personal experience. His trust of others is revealed in the sense of acceptance he encounters in his support group.

A sense of being different is present in Abe's protocol. He begins the interview telling the researcher that his story is more "unique" than others with an AICD, and he discusses how he is different from persons without an AICD. When asked about how his life is different or similar than what he thought it would be when the device was being discussed, he identifies that "people look at you like some kind of an oddball." He believes others perceive him as different, and are concerned about being shocked when he gets shocked. He concludes that more community education about the device has been helpful in getting people to accept him. He also indicates that, "I began to realize that maybe I was distancing myself from them, instead of them from me. About fifty-fifty I think was the way it was." These ideas also support the notion of acceptance, as his perception is that the acceptance of others increased over time.

Abe reveals that as far as he was concerned, there was no choice in the matter as to whether or not to have the device implanted. As he puts it, "They

didn't pull no punches. They said you either take it, or take the chance of not getting out of the hospital next time." Abe has a strong awareness of death and indicates that the AICD "is there for the purpose of saving your life." This idea undergirds Abe's process of acceptance and his decision to have the device implanted.

A sense of luck, and gratitude is conveyed by Abe. Throughout the experience of sudden cardiac death, he describes his son's opportune presence as "If he hadn't been here, I'd have been dead. But he was here, thankfully." He also describes the hospital event that led to the implantation: "They didn't know anything about this type of procedure, but luckily one of the young doctors had trained under Dr. (name) in (large city)."

Abe is very cognizant and precise in descriptions with regard to time. He divulges the exact month and year in which events occurred. He describes events exactly as they relate to time. The first shock was "three months after I got it." Statements related to the device, such as "good for another two months," are prevalent.

Abe's wife has provided the support Abe has needed through the whole experience. He plainly indicates when pointing to his wife, "That ole' gal right in there. That's the one, right there. Family support is the best support, and those support groups, the meetings we go to every month, that is the next

thing." The support group meetings were an integral part of Abe's acceptance of the device as he articulates, "You find out that you're not the only one having the problems, you know. It makes you feel good to know that there's just beaucoups of people who have these devices and have learned to live with them." The people in the support group are like him, so that he feels less different as he indicates, "I mean they are real princes as far as making a guy feel good about himself." Abe analogizes the support group to a "family," which he had earlier stated as the best type of support. Abe indicates that his primary physician is also a support for him, and that Abe was providing an opportunity for his physician to learn.

Abe is aware of the cost of the AICD and his hospitalizations. He states, "It's been about a quarter of a million dollars since '91." He describes his financial part in the process as "chicken feed" compared to what the insurance company has paid. He does not indicate the financial aspect of the device as burdensome.

Emerging Themes

1. There is a process of acceptance of the device. Initial fear resolves into accommodation.

2. The AICD as a treatment modality is linked to the cardiac history and is entwined such that the device is not separate from the cardiac problems.
3. Awareness of the device occurs only when in certain positions, including stooping over and when trying to sleep on the side of the implant.
4. Figurative language is used to personalize and describe the device.
5. Actual activities, other than driving, are not limited. Proximity to potential assistance from others influences where activities take place.
6. A sense of separateness from others and a uniqueness among persons with AICDs is evident.
7. The shock experience re-orders what has become disordered, changes disequilibrium to homeostasis.
8. Trust in others for information about the device such as health care professionals, and others with the device.
9. There is a feeling of gratitude toward something beyond oneself for surviving the sudden cardiac experience and having the implant that keeps it from happening again.
10. A deeper appreciation of life is experienced.
11. This participant has a keen realization of time.

12. There was no real choice in the matter of whether or not to have the device. Decision was made because of physician's recommendation and saw this as the only alternative.
13. Family support was essential to Abe in accepting himself with the device, followed by support from the AICD support group.

Situated Structure for Abe

The AICD is connected to this Abe's cardiac history such that the AICD as a treatment modality is not separate from himself or his health. The device is the exclusive prescription for his cardiac problem, as there was no choice in deciding to have the device or learning to live with the device. A deeper appreciation for life is evident through the experience of sudden death, and any inconveniences of the device are secondary. Living with the device was a dynamic transformation of thoughts and feelings about the device and himself that originated in fear which dissolved over time into a sense of near normalcy with a sense of uniqueness undergirding and persisting throughout the transformation to the present. Awareness of the device is most immediate during the course of certain activities such as stooping and sleeping, and surrounding the shock experience. The shock experience for Abe is a necessity that reorders his body and being that has become disordered. Living

with the device, metaphorically referred to as "an electronic guardian angel," is somewhat restrictive in that it limits driving and arouses a sense of discomfort and apprehension about being physically distant from others. The thoughts of potential difficulties are ever present. Having the device makes Abe different from other people, and effects a sense of separateness from others except his support system, which consists primarily of his family and members of the support group.

The whole experience is blanketed with a sense of trust in other people and a sense of gratitude toward something beyond himself and the health care professionals, for having survived death, and for rendering the circumstances for having the device implanted to keep it from happening again. The whole experience is well grounded in the notion of time.

Bob

Bob is a 54-year-old Caucasian male who works as a store salesman. He is a former truck driver but was uninsurable due to the implantation of the device six years ago. His last shock experience was five and a half years ago. He has had two bypasses, and his last hospitalization was two years ago when he had the device's battery changed. He lives in a small rural town with his

wife and 12 year old son. He has adult children who live in a nearby rural town, and has a large family network in his locale.

Bob begins relating his experience of living with an AICD with an explanation of the factors that led to the implantation: "I had high cholesterol which caused a lot of blockages in my heart veins. After a couple of bypasses, my heart would race, so they put it in." This indicates the confederation that the cardiac experience has with the AICD.

The device is not usually in Bob's immediate awareness. "I never think about it....I don't worry about it unless I get real excited and then I'll slow down and stop for a second and think about it, and maybe do something else different to keep it from going off." The device is immediately brought to mind when it is bumped.

Bob indicates that there is a sense of control over the device such that he can keep the device from going off. His usual activities have been altered by the device including his diet. "I used to eat steak, taters, and beans. Now I eat beans and taters and no steak." He goes on to say, "I'm a little more careful about what I do. If I get tired, I'll slow down." The actual physical structure of the device has mandated a change in activities for Bob. "It took me a year before I could lay on it and go to sleep. Now, I don't know if that was psychological. It didn't hurt. It was just uncomfortable." A trajectory of

accommodation is also evident in Bob's experience in that adjustment takes time.

Understanding of others is important to Bob. He describes situations where he is continually explaining the device to others: "I say, 'you've seen 'em take paddles and hit people to start their heart back? That's what it does.' And they'll say, 'Oh, okay, I understand.'" The trajectory is also evidenced in the way that others perceive Bob. He mentions a situation in the past to illustrate how others have gotten accustomed to the device. As recounted by Bob:

My nephew has a swimming pool. I had it (the device) about two years, and everyone knew I had it. I didn't think anything about it. I got up on the high dive, and before I hit the water everyone was out of the pool! They was afraid the thing was going to fire. (Laughs) Now they don't even think I've got it. It don't even cross their minds.

They've gotten so well adjusted that they don't even realize that I have one.

The device is a regulator. As a regulator there is trust in the function and efficiency of the device. There is a cause and effect relationship between Bob's activities and the device delivering a shock, such that the shock serves as a control for Bob's activities. Bob states:

My wife gets on me a lot. She says, "You're doing too much." I say, "Well it's not going off, so my heart must not be beating as fast as you think it is." ...As long as I'm not getting shocked, I'll just keep on doing whatever I'm doing. Now if it starts shocking me, I'll just do something else. That's why I don't get out there and run. Cause I couldn't run far in the first place, and this thing would probably go off before I got to where I was going. It don't hurt me to walk fast.

Driving is an activity that is an issue for Bob. Initially it was the implant that is "keeping me from going into my profession. You're not supposed to drive with it." The company that insured the truck company that Bob drove for would not insure Bob, so he had to find other employment. This did not eliminate the driving issue, as Bob continues to drive his own vehicle. "I'd rather be driving than walking. Me and the doctors went all through that for two years." He continues to drive as this is a source of independence for Bob. He rationalizes, "It is better for me to drive than to tire myself out trying to walk so far. If I tire myself out, or get my heart racing, this thing might fire."

The decision to have the device put in was a choice of life and a demonstration of trust in physicians. The trust in the physicians is transferred to trust in the device as Bob exemplifies:

I had no idea what to expect. They said this thing will keep your heart from tearing up more. I asked them (doctors), "What do you mean?" They said, "If your heart gets to beating as fast as it did, you'll never make it through another one." So that stuck in my mind, "Put it in doc." It's just like having a doctor with me.

A situation involving health care professionals who didn't understand the device is mentioned by Bob. Bob had experienced getting something caught in his throat and rupturing a vessel. He began spitting up blood and continues, "I wondered if it was the ICD, and I got scared. So I went to (hospital name). And they had no idea what an ICD was, what to do, or how to check it, or nothing. It was scary!" So trust and mistrust of the health care system is evident in Bob's experience. He trusted enough to seek help from persons in whom he had confidence only to find out they did not have ability to help. This resulted in the feeling that Bob identifies as fear.

Bob indicates that his wife and family are main sources of support. Physician's who are knowledgeable about the device have also been a source of support as Bob identifies, "They say I'm great. They don't tell me what to do or nothing. They just say, 'You know what to do. Just go ahead and do it!'"

Symbols in Bob's presentation of the device are evident when he describes the device as, "...just like a filling in your tooth." This is an indication that Bob has assimilated the device into his being. It is also evident that he trusts the device when he says, "It's like having a doctor with me."

Emerging Themes

1. The experience of living with an AICD is meshed with the total cardiac experience. They cannot be separated.
2. The device serves a regulatory function, in that the shock is an indicator that he is involved in too strenuous or too much activity. A cause and effect linkage is evident. This awareness limits activity that could cause the device to shock Bob.
3. Sleep position is altered due to the actual substance of the device.
4. There is a trajectory of living with the device.
5. Part of this trajectory is related to other's understanding of the device.
6. Decision to have an implant is an affirmation of life.
7. Trust and confidence in physicians knowledgeable about the device is exhibited.
8. Misplaced trust in a health care arena when the device was not understood resulted in feelings of fear.

9. A support system is evident through wife, family and physicians knowledgeable about the device.
10. Symbolic expressions of the device indicate assimilation and trust in the device.

Situated Structure for Bob

The AICD is not separate from Bob's cardiac condition. The condition led to Bob having the AICD, and living with the device is linked to his awareness of his underlying cardiac problem. There is a process of acceptance of the device. This is mediated by time and by Bob's belief that others have understanding of the device. The understanding of others is important in this process, as their acceptance and willingness to treat him similarly to everyone else enhances the integration of the device into his daily existence. Support of others, including his wife, family, and particularly his physicians, have been important.

The device serves a regulatory function, and a shock is the result of too much or the wrong activity. A cause and effect relationship is evident such that when there is no shock, the activity is acceptable. This is also the rationale for driving, which has been as source of conflict personally and professionally for Bob. Getting too tired from walking, necessitates driving.

This transcends physician recommendations, but not insurance regulations that caused him to have to stop being a truck driver. Activities such as sleeping position are altered to accommodate the physical presence of the device.

The decision to have the device implanted is an affirmation of trust in physicians knowledgeable about the device and an affirmation of life. The threat of death without the device prompted the decision. Trust in overall health care providers has been invalidated, and the experience resulted in a situation of fear.

Symbolic presentation of the device is revelatory of Bob's experience of the device. When allegorized as a tooth filling, it is clear that Bob considers the device a part of himself. Presenting the device as having a doctor in his company not only affirms his trust in physicians, but also conveys his confidence and security in the device.

Carl

Carl is a 63-year-old Caucasian male who has had an AICD for 36 months. Carl has a 27-year history of cardiac problems. By the time Carl was 60, he had experienced four myocardial infarctions and had undergone three coronary bypasses. The myocardial infarction experienced three years earlier left Carl with what he reports to be a memory loss surrounding the

events of the implant, but he is very explicit about the time of events and the names of persons and places. The interview with Carl was the shortest of this study, as Carl became easily fatigued. Carl is retired from the Army, and was working at a military base with a plant operations computer when he sustained his last heart attack. A few months after recovery and the implantation, he retired for a second time. During the last infarction, Carl experienced sudden cardiac death, and was comatose for four days. Carl has experienced only one shock, which was eleven months after implantation.

Carl is most aware of the device when he observes his body, when he takes a shower. He indicates, "It's like a sack that you look down at." He also maintains he is aware of the device, "If I bump or anything, or if I pick something up." Carl uses the metaphor of an "insurance policy" when describing the device and refers to it as a "lifesaver."

Because of his mental status during his last myocardial infarction, his wife made the decision for him to have the AICD. He conveys that "I was in the hospital about a month and I didn't even know I had it." He has the device as a result of his wife's trust in the physicians.

Carl had been told that the shock "would be enough to knock me down." The actual experience occurred when he was eating out. As he sat

down, he felt a shock and thought the table had shocked him. He described the shock experience as "just a shock."

Carl indicates that initially others misunderstood what the device was. They thought of it as a pacemaker and would ask Carl to show it to them when he first had the device implanted. "It's not even a subject of conversation anymore." Carl indicates that it has not interfered with his relationship with his wife as "she fusses at me like she always did."

Limitations in activity for Carl are perceived as the result of the underlying heart problem and not the device. Limitations include not climbing steps, not lifting heavy objects, or "just regular things that a heart patient's not supposed to do anyhow."

Carl indicates that the physicians have been helpful and supportive since his implant. He indicates that they call frequently. He does indicate some concern over the discrepancy in the information given him and his wife about the device, especially as it related to him being around electronic fields. This presents a trust issue for Carl as he indicates that "there should be no question if one's been told they need one. There should be no question." Yet the physicians have given Carl contradictory information, such that Carl has bypassed the physician's information and has called the manufacturers of his device for information.

Carl mentioned the expense associated with his hospitalization and the device. He describes it as "outrageous," but indicates that his insurance covers all of the expenses. He verbalized some frustration about the billing procedures from the institution. As Carl describes, "I didn't know who we owed and who we didn't...there was so much confusion...every department charges separate...it's the most ridiculous thing I've ever seen in my life. I told them after two years I would assume everything was paid and there is not use in sending me any bills after that!"

Carl expresses ambivalent gratitude for being alive. Carl concludes "I consider myself lucky, I guess." He perceives the device as something "I need to prolong my life." He states toward the end of the interview, "I'm just thankful that I got it."

Carl takes an antidepressant and states, "I have had a little bit of depression...I think its all of this." He indicates that, "You can make yourself sick feeling sorry for yourself."

Emerging Themes

1. Carl's awareness of the device is primarily when he is aware of his body, such as when he showers or when his body comes into contact with another object and he strikes the device.

2. Carl uses the metaphor "insurance policy" when discussing the device, and describes it as being "Like a sack you look down at, and it's there." He also refers to it as a "lifesaver."
3. Carl experiences a sense of uniqueness in his interactions with others.
4. Carl identifies that the uniqueness and difference between himself and others gradually diminished over time.
5. Carl is aware that the general public does not understand the function and purpose of the device.
6. Carl experiences incongruity in trust in others. He is concerned about the contradictions in information he has been given by persons who are in authority. He experienced trust in his wife's decision to have the device put in, but is continually information seeking for clarification.
7. Carl experiences ambivalence as he is grateful for being alive and for the opportunity of having the device, yet at the same time he is depressed.
8. Frustration with the health care system and the billing procedures were identified by Carl as particularly burdensome.

Situated Structure for Carl

The experience of living with an AICD for Carl is grounded in an overall sense of ambivalence. Carl is grateful for being alive and having the

device. The device and circumstances around his cardiac problems, including memory loss, have diminished his quality of life. Carl is depressed and expresses frustration over situations that involve the AICD. Situations that are most upsetting for Carl primarily involve interactions with health care professionals and the conflicting information that he has received about the device. He expresses exasperation with the health care system and the billing procedures from all persons involved with the implantation of the device. A fluctuating trust in others, especially health care providers and health care system operations, is tempered with a perceived lack of choice.

Carl identifies a sense of uniqueness that was most pronounced earlier, that has gradually diminished over time. The uniqueness separated him from the general public, but also made him a novelty, as he enjoyed showing the device to others. He is aware that others do not understand the function and purpose of the device.

Carl's primary awareness of the device is in situations where his body is uncovered or unclothed, such as when he showers; and in situations where his body comes into contact with hard objects that strike the device. Carl uses the metaphor "insurance policy" when describing the device, revealing a sense of security in having the device. The device is also referred to as a "sack you look down at" and a "lifesaver." The device has positive implications for

Carl, but these implications are entwined with opposing components of frustration and depression.

Don

Don is a 64-year-old African-American male who had an AICD implanted eleven months prior to the interview. Don is retired from the military and had been working as a civil service drug and alcohol counselor for the military base. He has a seven-year history of cardiac problems including a valve replacement. He experienced his first myocardial infarction one year prior to the interview, during which he sustained a memory loss and experienced several complications mandating hospitalization for a couple months. The defibrillator was placed and he was sent home. The memory loss remains an issue for Don, but he is very articulate and exact about dates and places. He has experienced one shock which occurred three nights before the interview.

Don identifies mixed feelings about the device when he returned home from the hospital, but identifies a process in understanding and accepting the device. Don indicates that, "It immediately gave me a feeling that I had something to protect myself. I had less of a situation to deal with." He goes on to say though, "Getting used to the defibrillator was a little problem."

The problem Don identifies is his lack of understanding about the device as he indicates that, "I didn't understand all about the defibrillator and how it worked." Once he understood the function of the device, he indicates that it allowed him to be active. "I was able to go back to church and do my trustee position, and by doing things, of course the defibrillator allowed me to do that."

Don's wife was a tremendous support throughout the hospitalization. The defibrillator renewed his ability to be active and took pressure off of his wife. As Don states, "The defibrillator gave me more mobility and I was able to take some of the pressure off of her." He engages in activities to help his wife. "I thought it would allow me to be active, and would take the pressure off my wife, because my big concern was to take pressure off of her." He concludes that he can do this and identifies, "All of this is because I didn't have to worry about anything, because the defibrillator was there to do the job."

The first and only shock Don has experienced was during sexual relations with his wife three nights prior to the interview. Of the shock Don admits, "I didn't know that it would be that jarring....I felt this WHACK, sudden jerk....It felt like a jerk forward, just like that. I had to jerk forward. There was not pain, just a 'poof'. I felt it around the back here, and in the

middle of the back. I thought someone had broken into our house and hit me in the back."

The shock experience led Don to believe that his actions will cause the defibrillator to shock him. "Just the excitement of the heart from a sexual act will bring it on. That's probably what did it." The experience also brought about a clearer understanding of the defibrillator. Don states, "Up to that time, I thought that each time my heart raced that the defibrillator stopped it, but that was the first time. I knew from then on." His initial security in the device was augmented by the initial shock as Don states, "Now my security has increased, because I know for sure how it will occur."

While he believes that the device allows him to be more active, Don does mention restrictions in activities related to the defibrillator such as lifting. Don describes a situation at church, "Then I thought about the defibrillator and decided not to lift the table. Anything that would excite the heart will cause the defibrillator to cut in. Lifting would have done that." He also warns, "You can only go so far."

He indicates that the device is more than just a device, and that it has a special presence. He says, "You see before, I had to walk **alone**, then I would get kind of concerned." Because of the device he does not perceive himself as alone. "Security is the thing! I don't fear doing things anymore. I

feel like if something happens and the heart races, that the defibrillator is going to kick in." Security is the result of trust in the defibrillator. The issue of security undergirds Don's whole experience of living with the AICD. Don uses the metaphor of a "security blanket" when talking about the defibrillator.

There is an awareness that physicians sometimes recommend removal of the device if the recipient does not seem to require the device, as demonstrated by infrequent or no shocks. This prospect is upsetting to Don. He states, "The doctor told me that after three years, if it didn't go off much, they might take it out. That got me real upset. I see no reason to take it out of there. I may need it and wish I had it." Later in the interview he declares, "There is no way I would have them take it out. That would be insane. To take it out would put me right back where I was before."

Don is unaware of the device on a day-to-day basis. His wife reminds him of the device. As Don states, "it really doesn't bother me at all."

Don states, "I don't even know that it's in there hardly, until I take a shower and look down."

The defibrillator has impacted Don's self-esteem. He imparts, "The defibrillator has given me trust in myself to do a lot of things." He also believes that the device enables him to be less of a burden to his wife and family.

Don is clear that other people "...really don't understand. They don't know what it is in the first place. They don't understand what I'm talking about." Don identifies his wife and his pastor as understanding about the device; these two provide the most support. Don also mentions understanding about the device in relation an incident at the airport. As the device sets off the metal detector, he requires individual consideration. He indicates that, "The first time they made me stand away, but now they understand." Being understood is important to Don. This point surfaces throughout the interview as toward the end of the interview he reflects, "Everything's been fantastic for me though...Just a lot of people don't seem to understand."

The expense of the device is part of the experience of living with the device, but the expense is worth the benefit of having the device. "It may seem expensive, but there's nothing worth life. The worry off the family would be as much as it's worth. If you have to have the device, the family won't have to worry."

Don's wife made the decision to have Don implanted with the AICD. "The doctor talked to my wife quite a bit and told her I was a good candidate for one because I was so active and all." The decision for life was made on Don's behalf. This is a reflection of his wife's regard for him, which is reciprocated in his desire to take burdens off of her.

Emerging Themes

1. Living with the device is meshed in health. The device cannot be viewed separate from the experiences that initiated its implantation.
2. The experience of living with an AICD is grounded in the security it provides. Although there is not a conscious awareness of the device except when looking at his body, Don conveys he is not alone because of the device.
3. Understanding the device and how it worked was important in the process of adjusting to the device. Understanding continues to occur.
4. Other's understanding the device is important.
5. Persons who understand are considered supportive.
6. The first shock experience enhanced comprehension of the device.
7. There is a linear cause and effect that exists between Don's activities and the device firing.
8. There are restrictions on activities because of the device, yet there is an emancipation from fear of another cardiac arrest. Limits exist with liberation.
9. Device is described metaphorically as a "security blanket" and identified in terms that relate to an amplified self-esteem.
10. Choice to have AICD was made on behalf of Don, and is an affirmation of his being.

11. Presence of the device viewed as congruous to life, outweighs the financial aspect of the device.

Situated Structure for Don

The experience of living with an AICD is merged with the heart problem for which the device is the treatment. The device cannot be viewed as separate from Don's cardiac experiences. Living with the AICD provides a strong sense of security, and a sense of accompaniment that is protective. A physical presence that is brought to immediate cognition in activities such as showering is transcended by an abiding ethereal presence that underlies Don's being.

Appreciation of the device is a process that continually unfolds as time passes and events occur that enhance understanding about the device. Approbation is amplified by understanding. Although the sense of security was immediate, a deeper regard for the device resulted after the initial shock. Enhanced understanding and appreciation for the device occurred.

A linear cause and effect relationship exists for Don between his activities and the activation of the device, such that shocks can be prevented by observing regulations imposed by the device. These regulations are paralleled with a sense of freedom provided by the device such that a symmetry between

the restrictions and freedom exists that is maintained by the presence of the device.

The importance of the device makes the understanding of others significant. Family and a pastor who know about the device and have a comprehension of the device and its purpose are most supportive. The wife is central to his existence. Don's wife made the choice of life for Don, and a profound appreciation for her being is linked to his being. Occasions where others are encountered who do not understand the device are inconsequential, as the device is a cardinal aspect of Don's identity.

The device is a "security blanket" that protects and guards Don's existence. The device is congruous to life and quality of life. The contribution that the device makes to the caliber of life outweighs the financial aspects of the device.

Eve

Eve is a 51-year-old Caucasian female who has a twelve-year history of cardiac problems that began with a myocardial infarction at the age of 39. She has had numerous bypasses and has experienced sudden cardiac death on three separate occasions. Twice she has been revived by external electrical cardioversion; once, the impact of hitting the floor when she fell revived her

immediately. She sustained another myocardial infarction three years and four months ago. During that hospitalization she had several episodes of ventricular tachycardia, at which time an AICD was implanted. Eve lives with her husband in a small town, in which she was born and reared. She has three children who live in a nearby town. She works part-time as a church secretary.

The history of heart problems for Eve is interwoven into Eve's experience of living with an AICD. When asked about the length of time she has had the AICD, she responds with a brief answer:

Three years and a little more. I was having a great many blockages. I was developing blockages like in three months from where I had balloon surgery three months before. I would go back because I would get in trouble again and there would be a blockage, and they would look at earlier x-rays...(She tells her history for another three minutes before mentioning the device).

A process of appreciation for the device is part of Eve's experience of living with the device. As she describes, "At first my husband and I were scared to death." There is concern and anticipation about the device initially. "You just kind of wait to see what it's going to do. And that didn't last long.

Probably two or three months, when we decided we would go on with our lives. You cannot live on a knife edge. You've got to on with things."

This process was augmented by the initial shock. "But once it finally fired, after 18 months, and we saw that it didn't do anything to me, you know, then it was a whole lot better. If we could have made it fire earlier, it would have been a lot easier to live with." Before the first shock, Eve experienced periodic chest pains that she interpreted as the device activating. Once she experienced the actual shock, she knew what to expect. "If it had fired earlier, I would have been a lot better off." The notion that the process is continual is further supported by Eve's statement, "And I really took a big leap about three months ago. I decided if I really wanted to do something, I really could accomplish it."

The decision to have the device implanted was an affirmation of her concern for her mother and her husband. It was not an easy decision for Eve, as she recounts:

My husband and I decided that I didn't want it, that I would rather take my chances....But then looking at my mother, I thought if I don't have this done, she will never forgive my husband. Once I'm gone, she will turn on him and say, "If you had made her have that device put in, this would not have happened." And my mother was the basis for me

deciding to have it....My mother was the cause of me having it put in.

Because of what I thought it would do to her. It's hard to lose a mate, or it's hard to lose your parents, but losing one of your children is the worst that can happen to you. I didn't think she could take it. I

couldn't get her ready for it. So we had it put in.

Eve expresses fear of becoming dependent on others and becoming a burden. She is aware of the presence of death, but does not fear death as much as she fears a compromised quality of life and becoming a hindrance to others. "And I'm not afraid to die. I'm afraid of being an invalid. I'm afraid of being a burden on my family. But dying, that's not a fear for me."

Eve has a strong sense of security in the device that has been amplified by the shock experience. She says of her three shock experiences, "I dodged three bullets. It's fired three times. Three times I would have been dead." When talking about the device, she says, "You know, it's a safeguard." She is grateful for the device when she experiences the shock, as it is a reminder for her that it has saved her life. She says she gets "giggly" after a shock, but explains, "I think that's the mental knowledge of knowing what has happened. Just kind of thankful that this thing has done it again! I'm very thankful that it fires, cause I'd have been gone."

Eve's independence was jeopardized "when they first put this box in, they wouldn't let me drive. And that **makes** a difference in your life." Not being able to drive kept her from going to church and doing things she wanted. "I couldn't go back and forth to church without my husband taking me."

Support for Eve comes primarily from her husband, family and her spiritual faith. Her support does not come from others with an AICD, and this is not even within the scope of her consideration. She says of support groups for persons with AICDs, "I think that's people who can't handle their own problems, and try to lean on other people. I can handle my own problems. I have the Lord. I have my husband. I have my family. I don't need any other support group." Although Eve can handle her own problems, she finds support and comfort in her husband, family, and her notion of "the Lord."

Eve uses humor to conciliate the device to others who are important to her. She mentions, "My friends are people I go to church with....They really care about me. They really do." A sense of caring comes from this group of people who are in essence a support for Eve, although she never identifies them as such. It is with this group of people that humor is used. "In fact we teased at church a lot about it. If we could just get everybody to hold hands

and pray that the box would go off, we'd get a little jolt, and we'd get something done. We'd think it was the Lord. We've teased about it."

Eve identifies certain activities that bring the device to her immediate awareness. Activities in her normal living patterns that the device impacts. "Sometimes I would put on clothes that hurt it. Sometimes it will be sore, for just no reason. Gas hurts it, pushes it around in its pocket. But I don't realize I have it most of the time."

Eve uses the term "the box" consistently in referring to her device. When she speaks of others or the device in generalities, she uses the term "AICD." When she speaks of her device, the device is referred to invariably as "the box", or the pronoun "it."

Emerging Themes

1. The device is not a separate entity from the cardiac experience. The cardiac history and AICD are parts of a whole experience of living with an AICD.
2. There is a process of acquiescence to the device that transpires over time and is enhanced by experiences with the device such as the first shock.
3. Fear is directed at the unknowns of the device and toward becoming a burden to others.

4. Choosing to have the AICD was an affirmation of values and the people in her life.
5. The device provides a sense of security.
6. Gratitude toward the device for its proven life saving intervention.
7. Recommendations surrounding the device from persons knowledgeable about the device infringe upon independence, especially the issue of not driving.
8. Support is evident from husband, family, people in the church, and in the Lord.
9. Humor is used to conciliate the presence of the device to others who are important.
10. Activities of daily living sometimes result in the immediate awareness of the device, such as gas pains, or particular attire.
11. The device that is part of Eve and her device is symbolized by the term "the box" where devices who are in other people are referred to as "AICDs."

Situated Structure for Eve

The device is not a separate entity from the experiences associated with cardiac events and hospitalizations. The device is a part of the whole cardiac experience and cannot be sequestered. Living with the device is an

acquiescent process that occurs over time and is facilitated by experiences with the device, including the first shock which leads to an increased understanding of the device for the participant. A sense of security is reaffirmed by subsequent shocks that the participant interprets as having saved her life. The sense of security is accompanied by gratitude for its life-saving intervention.

Fear is directed toward the unknowns about the device, and not toward death. The greatest fear is identified as diminished quality of life of others in her life, and for becoming an incapacitated.

The choice to have the AICD is an affirmation of values. It brings a heightened awareness of important aspects of life. Choosing to have the device is a reaffirmation of the importance of the people in her life, particularly her mother and her husband. It is an endorsement of what is, not what could be.

Support comes from family, friends, and "the Lord." Friends are primarily persons in her church for whom the spiritual being is a center. The presence of this support negates the need for support from other sources. Humor is a vehicle that promotes awareness and acceptance of the device by others from whom she finds support.

Recommendations surrounding the device infringe upon the independence of the subject's being. To follow the recommendations mandates

reliance on others, particularly in the case of driving. Other activities associated with daily living sometimes result in immediate awareness of the device including gas pains from eating, or clothing that is restrictive and reminds Eve of the device through soreness.

Personalization of the participant's device is evident in her reference to her specific device as "the box." Reference to "the box" clearly identifies her AICD as opposed to AICDs in general or another person's AICD. It is as if she has named her AICD, "the box."

Fred

Fred is a 70 year-old-male who was implanted with an AICD 11 months prior to the interview. Fred has a 23-year history of cardiac problems. He has had two myocardial infarctions, one three vessel bypass, and a subsequent angioplasty to open one of the grafted arteries. Eleven months prior to the interview, Fred experienced sudden cardiac death while at a hospital being screened for elevated glucose. At that time he underwent a five vessel bypass, and the decision was made to implant an AICD.

Fred has a Bachelor's degree in engineering and is a former industrial engineer. He is presently retired, but remains active with a state of the art

workshop, where he continues to weld, and create recreational playground furnishings for his grandchildren.

Fred is very specific about describing his AICD. He uses the actual brand name from the manufacturer. He is very knowledgeable about the device and its electronic and mechanical constitution.

Fred reflects on living with the AICD and indicates that there is a difference in his outlook now and when he first left the hospital with the device. As Fred explains, "At first when you get out of the hospital and all, you're kind of cautious and nervous about it, you know." For Fred at the time of the interview, "it's not any different from living any other time."

Fred explains that he needs to be cautious around magnetic fields. As stated by Fred, "The only thing I have to look out after is magnetic fields. I have a pretty good sized shop. It's not a home 'do-it-yourself' shop. I have metal lathes and shavers and things like that where I can rebuild engines." He is aware that with his device when he is "in a field that is too strong, I'm just not protected."

When deciding to have the AICD implanted, Fred relied upon the recommendation of the doctor. He placed total trust in the health care professionals. As related by Fred, "They ran the tests and decided that I would be a good candidate and asked me if I agreed to it. I said 'yeah.' You

know, he's the doctor." Fred's trust in physicians is reiterated later as he recounts the decision to have the implant. Fred states, "I left everything up to the doctors....And I think it's dealing with people that you know, and if you have a lot of sense of responsibility in them, then, if they thought it was good, I would go along with them." So Fred is not only trusting the health care professionals, but also his estimation of their sense of responsibility.

Although Fred has curtailed his activities slightly, he remains active. He explains, "I do everything I used to do except...I used to do a lot of boating. I skied up until this year. Of course, they advised against skiing. It's not the...if you fall you can hit pretty hard, you know. And they just said it in a good way, 'We don't think you ought to do any contact sports.'" Fred also indicates that he has stopped "snorkeling" because he does not want to put "pressure on the thing." It is apparent that if Fred sees the logic in the recommendation, then he is more willing to cooperate with it.

This bears itself out as Fred explains that he continues to drive, in spite of the recommendation not to drive. According to Fred, "I see no difference between you and me driving. You have no idea when you're going to have a heart attack. There's no way to guess it." He explains that when he is shocked he maintains complete control, and that losing control of a vehicle is unlikely. He mentions the driving issue throughout the interview and explains

later, "I do defensive driving. I keep myself, in case something should happen on a highway, I stay in the right-hand lane so I can pull over to the side and not get caught. And usually the only time I stay in the center lane is when I've got to turn left or have to, you know, I'm prepared. So I really, for me, I can see no difference in making a law that you couldn't drive, cause you have no idea ...I mean you could have a heart attack or stroke or something like that."

Control and independence are two attributes that Fred values. When discussing his first shock experience, he reiterates, "And I had complete control. I would say it didn't last over a second. Maybe a second and a half. I had complete control." Then Fred mentions the driving issue again. Related to the second shock experience, Fred adds, "And, ah, it didn't bother me in the least. So talking about driving, then I never lost control. I was eating breakfast and all like that. I can see no problem, if it goes like that all the time cause you never lose control of your car."

Fred has had two shock experiences. One time as Fred relates that prior to the shock, "You start feeling faint, and your eyes start getting blurry just a little bit, you know. You ever been knocked out? Well, that's what it feels like." In describing the same situation later, Fred relates that after the shock, "It was finished with. The dizziness and everything was gone. Brand

new! Ready to go." For Fred, the shock is renewing, yet at the same time a reminder that things had become disordered, as he states, "Actually, I wished it had never gone off. Cause it means everything is **perfect** when it doesn't."

He does indicate that after the first shock he was scared. "It's just like being in an automobile accident. When it's happening you don't get scared when it's happening. It's afterwards that you get scared." Of the second shock experience Fred recounts, "I knew what was happening and it didn't bother me in the least. You know, it would be just like me sitting here, now, and it would go off and I'd jump right then."

Fred is aware of the device occasionally. "You know when you carry things like a case of this, or something. You always put it against your stomach. You might forget and that's the only time." Fred is also careful to stand away from his drill, rather than holding it against his stomach. He addresses the magnetic field restriction and thinks about the device when he is in his shop. He sought clarification about this from the manufacturer of the device rather than the physician. He talked to one of the vice presidents of the manufacturing company to get the information he needed.

Fred also admits that he has avoided traveling long distances because of the device. As Fred tells about a group of friends that traveled outside of the United States, "I didn't want to go with them because I didn't want to get out

of the country because I just didn't want to get out of the country because it had never gone off at the time.... I didn't go with them this year, because I just didn't want to take a long, big, well, when I was in good health, I'd be going like a steam engine. I didn't see any sense in going over there and putting yourself through the stress, you know." The distance from trusted health care was a major concern as Fred later in the interview states, "I didn't want to end up in some place like Mexico, Italy, or Spain, and they might not know what to do. On the ship they might not know what to do."

Fred is keenly aware of time. He is very explicit about dates throughout the interview, and mentions the actual time he received his shock. With the first shock experience he explains, "I would say it didn't last over a second. Maybe a second and a half." Concerning the second shock, he reveals that "...it was all over in two seconds." Concern about time in relation to battery efficacy is also mentioned.

Awareness of the body is a regulatory mechanism for Fred, such that messages from the body keep one in balance. He states, "You can feel when you, your body will tell you when you've gone too far. And I think your body tells you certain things, like there's not sense in going out there and trying to pick up three hundred pounds of weight over your head."

Fred also closes the gap of being different from others by his participation in the support group. He describes the support group as a place where, "They have the meeting broke down into groups where each group can sit down and talk and tell their problems. I like to listen, just to hear. If you listen, you can hear a lot of things."

A positive mental attitude is conveyed by Fred as a key in accepting the device. He describes a conversation with a physician friend who told Fred, "I can go in and fix you up, but your attitude is the biggest thing." This advice has been assimilated by Fred as he explains, "I feel a person that stays very active mentally and physically will do a lot better than a person who gives up....A person who has a defeated attitude usually won't make it. And I've always had a (pause) I've been competitive in sports and all, I needed to **win**, you know, so I have had no trouble whatsoever."

Emerging Themes

1. One becomes accustomed to having the device, moving from initial caution and anxiety to the perception that the device makes no difference. The experience of the first shock makes subsequent shocks less distressing.
2. Caution remains manifest in remaining close to persons knowledgeable about the device, and who can help, if needed.

3. The device is viewed as a protector, but the protection is conditional.
Under certain circumstances, such as magnetic fields, the protection pauses.
4. Trust in the health care professionals is imperative, yet there is some information about the device that requires seeking additional information from persons who know all of the intricate mechanical details of the device.
5. Control and independence are important, as there are some things that cannot be controlled, it is important to direct those things that can be regulated.
6. Recommendations to alter activities must have a logical reasoning behind them in order to be followed.
7. Alteration in daily activities is minimal, although driving is an issue.
Rationale for not following physician recommendations related to driving is presented several times.
8. The experience of the shock reorders a body that has become chaotic, and renews the individual.
9. The body sends messages to maintain stability of the individual so that the individual does not mistreat him or herself.
10. Time is a critical component of one's being and awareness of time is important and meaningful.
11. The support group ameliorates the sense of being different.

Situated Structure for Fred

The experience of living with an AICD for Fred is grounded in a conflict of control. There is an acknowledgement that there are some things that the individual cannot govern, which makes command over the entities that can be controlled significant. This is lived out in the processes of information gathering and the acceptance of information. When Fred understands the logic and rationale of certain behaviors, he is willing to conform to the practices. If justification for a practice is not present, Fred applies his own reason to his practices. This is exemplified in his driving practices, which Fred continues and for which he readily offers explanation. Alteration in routine activities is minimal, but some sporting type endeavors have been curtailed.

Trust in health care professionals for the necessity of the device is unquestioned; yet Fred does not perceive the actual mechanics of the device to be medical knowledge. Seeking information from authoritative sources, including the manufacturer of the device, is important to the subject.

Having the device implanted involves a trajectory of acceptance that begins with caution and nervousness. These feelings are alleviated to some degree after the initial shock, after which the subject knows what to expect. Caution persists in living with the AICD, particularly with regard to the proximity to others who can be of assistance if needed. There is security in

having the device, which is referred to as a protector; but at the same time, there are restrictions on that security and protection. Closeness to others who are knowledgeable about the device improves a sense of security, and being around others with the device connects Fred to others so that his sense of being different is lessened.

Fred is frequently aware of his corporeal body and how it sends regulatory messages to maintain its stability and equilibrium. The shock experience restores a body that has become turbulent. All experiences are grounded in the awareness of time.

Gail

Gail is a 63 year-old Caucasian female living in a very rural area. She is retired and helps her husband with his business. Gail had a heart attack five years earlier at which time the physicians discovered an aneurysm on the left ventricle of her heart. She experienced four episodes of sudden cardiac death around the event of the repair, and each time she required cardiopulmonary resuscitation, and external cardioversion. She has had her device for four years and nine months and has experienced three shocks.

Gail begins her story with the cardiac aneurysm that her physicians discovered three months before she had the AICD implanted. She describes

her sudden cardiac death experience and the need to be resuscitated. Her story clearly expresses that the AICD is not a total separate entity for Gail. The AICD is a treatment modality for Gail's cardiac condition, and as such, the condition must be explained. Gail states, "It's hard for me to separate those two. It really was because that was the whole reason for having it!" When asked about the AICD, Gail explains, "I had an aneurysm on the lower left ventricle which Dr. P. had to remove. And they did CPR on me, oh gosh, I guess three or four times....And of course, each time that I blacked out, why they had to shock me to bring me back." When she went to surgery, the physicians placed the leads for the AICD in Gail, in case she needed to have an AICD placed. Gail states that her acceptance of the device was influenced by her illness. She explains that she was so sick, "it took me a long time to decide I wasn't going to die." The device is perceived by Gail as a reminder to others of her illness. She mentions people asking her husband about her and she indicates, "And every once in a while I almost resent it a little bit because I want people **not** to remember how sick I was. I want them to think of me as well. That I'm well now. That they don't have to (pause) but they still do after four years, people still think I am a little bit different than other people."

Gail mentions other people's lack of understanding about the device as a concern, and then as a novelty. Others' lack of understanding allows her to educate others. Of this Gail says, "When I did educate people, and that was fun....I had more fun then cause I knew so many of the nurses up there and so many of them knew me. And I had them come from all over the hospital, secretaries and what have you came and wanted to feel my AICD, or see it, or feel of it and want to know about it....But I really had fun teaching everybody about it." The uniqueness has both tones of enjoyment and frustration over lack of understanding.

Gail explains that the shock experience "scared my husband." It occurred when she was asleep at night. She called the physician immediately for instructions and reassurance. As she indicates, "I don't know why. He just was very reassuring to me, and I went right back to sleep. Don't ask me how I did that cause I know I was nervous." Reassurance from physician was comforting to Gail on several occasions.

Gail explains that it took time to get used to the device and the idea that she was going to get shocked. "It wasn't hard to get used to being with it. I think it might have been difficult to think I was going to maybe get shocked, but I felt that's what it was there for. And slow, but sure, I started to do everything that I wanted to do." The device presented Gail with an

ambivalent feeling of fear and comfort. Fear the device may go off, but comfort in knowing that it was there. It took time for Gail to get accustomed to the presence of the device. As she states, "It took me a long time to get used to it because it was just a big box sitting there, you know."

Awareness of the device occurs whenever Gail makes certain movements such as, "If I pull up or turn sideways, it just shoots really sharp pains. I've had a hard time getting used to it. I don't think that will get any better because it's right here, but they're still experimenting you know." Gail was most aware of the device, "When I tried to sleep at night. Turning over on my left side took me a long time to be able to turn over on my left side." Some activities, such as "bending over" also reminds Gail of the devices's presence.

Gail is aware of the device's impact on her shape, and this affects her body image, as well as the way she dresses. She explains that as the result of the device, "You wear a lot bigger waist size. I have to adjust all my clothes. But I did find out one thing that was interesting and that I had the worst time with pantyhose. I could not wear pantyhose because you can't wear anything that is tight around your waist, not just because it would interfere. I don't think it would interfere with the wires. But it's uncomfortable." Gail accommodated the device after trial and error by ultimately wearing maternity

hose. This was an innovative, creative means to accommodate the device.

She also indicates that she learned to choose dresses differently. "I don't get a bigger size dress, much bigger. I just have to get a different style now."

Later in the interview she indicates, "I've gotten more stooped, and I think some of that is because this is a pull on your stomach."

Driving is an issue for Gail. Gail's geographical isolation and need for independence were the impetus to this decision. Gail is very careful when she drives, and has modified her driving style with regard to speed and following other vehicles. About persons with AICDs who drive Gail explains, "They just do not want to give up their driving. And it really is a problem and I feel guilty, I really do feel guilty at times."

The first two shock experiences occurred when Gail was asleep. She was unaware of what was happening until she experienced the shock itself. During the third shock, Gail was not asleep. Her account of that experience is more descriptive. She recounts, "And I thought I was going to faint. I just got, everything started turning black, and I started to tell my husband that I was going to faint, and it shocked me. Now I mean I hit my chest so hard with both fists, it just really was a tremendous shock. If I hadn't been sitting down, it would have knocked me over, I know, but it didn't and so. It scared everybody half to death and I said, 'I'm fine. I'm all right. I'm all right.'"

There is a sense of disequilibrium, the shock, and then the feeling of normalcy. As with her husband during the first shock, Gail indicates that others are scared.

As a result of the shock experience while awake, Gail has become aware of bodily changes that occur before her shock. Since that shock, she recounts, "I have had very pronounced presymptoms of a shock after that and I knew what it was because I had that one." Whenever those symptoms reoccur, she grabs onto a close object and starts to take deep breaths. She states, "Then I haven't been shocked, it sets itself, my heart sets itself." Gail recounts an episode in a store where this occurred and deep breathing kept the device from shocking her. These episodes and her action indicate that Gail perceives she does have some control over her heart, and there are actions that she can take to put her heart back into a normal rhythm which keeps the device from firing.

She indicates that there was a progression in acclimating to the device and the thought of not dying. She was initially more concerned about death, than the AICD. Of the AICD Gail indicates, "I did think if I did too much I might get shocked with it, and nobody likes to think they're going to get shocked." She is aware that, "I probably would have given you a lot different answers if it had been the first year that I had one instead of four years later."

In relation to other people, Gail believes during a shock experience, "If you're touching somebody else, or they're touching you, they're going to get shocked. It might not be as hard as yours...You don't think about it much."

Gail is involved in water aerobics and does not concern herself too much with being shocked. Her concern is related to distance from others if she should be shocked. As she explains, "But don't go swimming alone, because if you did black out, you could go under the water." Gail's dilemma in this activity is that the instructor knows Gail has an AICD. "So she kind of keeps tabs on me. And that kind of perturbed me at first. That and driving are the only two things I think that I had to really, that I was concerned about." Gail wants to be independent, but situations surrounding the presence of the device made her dependent, or feel dependent especially if someone must "keep tabs" on her.

Gail associates death with being alone. Although there is security in the device and its function, there is fear of being alone. As expressed by Gail, "You're very afraid of being by yourself when you first get it. Even though you know it can shock you, you don't know where you're going to be when it shocks you....I would imagine that anybody feels very terrified of being by themselves, unless you're (pause). It's an easy way to die. It really is." She also recounts, "For a long time when I first got it, I couldn't go to sleep by myself unless my husband got in bed with me."

Death is a topic that continually emerges in the data. In relation to the AICD and life-support, Gail mentions, "If you just didn't want to live any longer, or you just didn't want that tube, you could have it turned off." Gail mentions that she and her husband had made "living wills" two months prior to her aneurysm discovery. Prior to being approached about the AICD, Gail heard one of the physicians say "If they don't do something with this woman, she's not going to make it." The physicians approached Gail and her husband and she understood, "there was no chance for me to live without it. There wasn't a choice." Gail's husband's concerns were eased with relation to the living will when the physician told him, "We're not doing this to keep her alive. We're doing this so she will live." Gail chose life when she chose the AICD as she concludes, "There was no way for me to live without it."

Gail's awareness of death results in a reverence for life. Gail indicates, "I think I have a much bigger respect for life and death now. And I think about death more and the consequences of it....I think that when you've had that much of an illness, or you have got an AICD, or something that is there to strictly prolong your life, then you have a lot more respect for your life, and the good days, and your good health that you've got." Death and the notion of death cannot be separated from the notion of life.

Gail indicates that a support group is beneficial for other people, but not for her. She perceives herself as being different in that, "Nobody else had one and all these strange things I went through I didn't have anybody to ask." Earlier in the interview she mentions, "I've had mine since 1990 and I don't believe they started even doing this much before 1988. I think (hospital in urban area) did the first one." Not only did she perceive herself as different, but very isolated. Isolated geographically as indicated by, "Here I was way out here."

Gail conveys herself not only as different, but also alone. This idea continues throughout the interview as she mentions, "I thought I was going to die, and it took me, with no one to talk to except my husband, and probably my husband worried more than I did about it. I was slow getting back to not worrying." Gail continually assigns feelings related to her and her situation to others. Others are important to Gail, and the device makes her different.

Gail indicates that a positive attitude was important to her recovery from surgery and her acceptance of the AICD. "And you sure can't feel sorry for yourself. You've got to get past the point to where you're not just an invalid....I think you could, it could very easily have made an invalid of me had I let it."

Gail indicates that getting more information, not at the time of implant, but afterwards would be helpful. As she indicates:

I think people with something like this need to have some way of getting more information or of just asking questions that they don't think are silly. So many things happen to you now, I don't even remember, because I've had it so long I don't remember a lot of things that probably went through my mind and the things that upset me, or what have you. But if there was somebody around, or somebody that knew, that you could talk to, or ask questions of. And it was difficult when you've got something so unusual that there's nobody next door, or nobody that you can just pick up the phone, and you don't like to call long distance to talk to a doctor. You couldn't get them anyway. They would have to call you back. By the time they call you back, you're probably already over your anxiety.

This statement confirms Gail's sense of isolation, being different, and desire to have had more information. It also indicates the awareness of anxiety related to lack of knowledge about the device, in that questions continually emerge.

Emerging Themes

1. Having the AICD cannot be separated from the cardiac problems, history, and sudden cardiac death experience. The AICD serves as a reminder.
2. There is an awareness of other people's reaction to her shocks as fear. She projects fear to people who see her get shocked, including husband and bystanders.
3. There is a trajectory of acceptance of the device, and a gradual alleviation of the fear that surrounds having the device.
4. Common activities of turning and movement are reminders of the devices presence and occur regularly, even after four years.
5. Gail experiences difference from others who have the AICD because of cardiac history. Being different from others who do not have AICDs is a reminder that she had the cardiac problems.
6. Perceived lack of understanding from others about the device is disturbing. The action of teaching provides a sense of being novel that is enjoyable, which is incongruent to the feelings of isolation that occur as the result of the device's presence.
7. Geographical distance from health care professionals and others who understand the device is fearful.

8. Body image changes with the AICD. These changes created the need for problem-solving relating to dress.
9. The experience of being shocked is preceded by feelings of disequilibrium. The shock reorders what was disordered.
10. The initial shock is followed by anticipation of a second shock.
11. Constant conflict with independence and dependence as the result of the device. She wants to be independent, but fear of being alone results in reliance upon others.
12. The desire to be independent results in Gail's driving, which generates as a source of guilt.
13. There is an appreciation and respect for life and death as a result of her cardiac problems, and the AICD serves as a reminder.
14. Acceptance and accommodation of the device would have been facilitated by more information and follow-up. Information given at the time of the device was implanted was forgotten, if given. The importance of health care professionals giving continual information and being accessible is evident.
15. Health care professionals who have knowledge of the device are unquestionable authorities and are very reassuring when contacted with concerns.

Situated Structure for Gail

The experience of living with an AICD is meshed for Gail with the circumstances that surround her cardiac problem, her hospitalizations, and her experience with death. The AICD serves as an ever present reminder of all of these events. At the same time, the AICD is the reason Gail feels she is still alive. The cardiac problems, of which the AICD serves to remind Gail, have resulted in a profound sense of appreciation of life and death.

There is a trajectory of acceptance of the device and a reduction of fear that is experienced initially with the device. Assimilation and accommodation of the device could be facilitated by more involvement from health care professionals and more sharing of information. During the course of cardiac events and decision to have the implant, was not the time to teach Gail all that there was to know about living with the device. Gail felt that this should have been done continually on a follow-up basis, and that more accessible health care would have helped her adjustment. Gail finds that once contacted that the knowledgeable care professionals are very reassuring, and unquestionable authorities about the device and how she should live with the device.

Gail's fear is also the result of geographical distance from persons who are knowledgeable about her health state and the device. Gail endeavors to bridge this gap by teaching others about the device, including health care

professionals unfamiliar with the device. This also closes the rift between her and others. It relieves her concerns about others lack of knowledge and understanding of the device. The presence of the device has mixed implications for the subject in her relation to others. She is different from others with the AICD because of the extenuating experiences of hospitalization, and being around persons with AICDs reminds her of her imminent death experience. Being around people who do not have AICDs reminds her that she has cardiac problems. Yet on occasion Gail enjoys a sense of novelty in having the device as she educates others.

The experience of being shocked is preceded by feelings of disequilibrium, which the shock transforms to bodily tranquility. An initial shock is followed by anticipation of a subsequent shock. Fear is projected onto others who witness a shock experience by Gail, as she remains keenly aware of the reaction of others.

Gail experiences conflict in dependence and independence as the result of the device. The desire to be independent is laced with the fear of being alone. This conflict results in anger at others for watching out for her and a sense of guilt for continuing to drive. Inability to drive would necessitate further dependence such that Gail has made the choice to deal with the guilt from driving rather the feelings of dependence.

Awareness of the device is intensified with common movement activities and turning. Some common practices, including sleeping, required some adjustment. Awareness of her body as the result of the implantation necessitated adjustment in clothing choices and creative alternatives to former apparel, including the utilization of maternity panty hose to accommodate the change in body structure.

Helen

Helen is a 62 year-old Caucasian female who is a retired factory worker. She had a myocardial infarction 14 months before the interview and has her AICD for 13 months. While in the hospital, Helen experienced eight shocks from her defibrillator. She experienced no shocks for a year, then experienced one four weeks prior to the interview. She lives in a very rural area with her husband. They have no children.

The AICD is ever present on Helen's mind. She begins the interview by stating that, "It's something you're aware of all the time. Well, I am." Helen conveys that even when she is involved in activities such as watching television, she will think about the AICD.

Helen experienced her first shocks in the hospital. She had a temporary pacemaker put in at the same time, after experiencing five shocks

close together. The nursing staff thought that the external pacer might be having an interaction effect with the AICD and when the external pacer was turned off, the shocks stopped. Helen experienced two more shocks in the hospital when being tested.

Driving is an issue for Helen, as she mentions early in the interview. When asked when she is most aware of the device, she answers, "I think when I am fixing to drive I think about it. Now I haven't drove since it (recently) fired off, cause I've been a little bit scared to....I feel like I'm a little bit afraid. If it was to go off, what would happen? You know, I wouldn't want to hit anybody or wreck the car or anything like that." Apprehension about driving is a concern. Helen is also aware of the device around cordless phones. Although not certain of the effect on the device, she perceives it as creating an electromagnetic field.

Helen tells others about the device and informs them that if they are touching her that they might feel a sensation if she gets shocked. At the beauty parlor Helen explains, "I've told her, too, when she's doing my hair, if this thing fires, she's going to feel it too. But not like I will, but she'll feel it." Concern and fear of shocking others is mentioned other times throughout the interview.

Being different is experienced by Helen. She acknowledges, "I am the only one around that's got one." Being different for Helen, though is "just something I don't worry about very much."

Support from others is from, "friends and family, and different churches around." Prayers from others "does the job" according to Helen.

Helen is also aware of the way the device changes her body. She mentions how certain things she wears make the device more visible to others. "You can see the device through my clothes, you know, especially in the winter when I was wearing something like a turtleneck, you know, and you could see it." Helen indicates that "everybody thinks I've got a pacemaker. That's common."

Helen has experienced a chirping sound that she interprets as a warning that the device might be getting ready to fire. She sought information from her physician, which conveys her sense of trust in the physician who put the device in her. "But he said, 'Don't worry about it. It doesn't sound like your batteries are down.' So I didn't. I didn't worry about it." Helen's trust in her physicians is also evident in the decision to have the device placed. After moving from one hospital to another for testing, Helen explains, "And he said, 'The only thing we can do is go with the defibrillator if you will have one.'

And I said , 'Well, I'll take it.' Because what else do I have besides that you know. "

When relating an incident where she was asked to talk to another AICD candidate, Helen maintains that she told the lady, who turned out to be a friend, "Opal, it's just like me. We don't have a choice and it's no big deal." Trust in the physician and lack of choice in the decision to have the AICD are evident throughout the interview.

Trust in the device is dampened by a fear that the device might malfunction. She does not take antiarrhythmic medications because of the side effects. As Helen explains, "Just rely on this." She mentions the possibility of malfunction a couple of times and then directly addresses the issue by saying, "Although the worst thing I can think of that would happen was its malfunction. That creeps into my mind every once in a while, but I just don't think about it very much."

Emerging Themes

1. Awareness of the device for Helen is continual.
2. The presence of the AICD is bound to the experiences of hospitalization for cardiac problems.

3. Concern about driving is expressed in relation to recent shock, for fear of what might happen and the fear of hurting someone else.
4. Awareness that the device might affect others is a consideration for this participant.
5. Support from others is identified as support from friends and family.
Support is also in the form of prayers on her behalf.
6. Uniqueness and being different is expressed.
7. Modification in attire is undertaken to accommodate the device.
8. Trust in physician is evident in information seeking, and decision to have the device.
9. No choice perceived in having the device implanted.
10. Trust in the device is ambivalent as there is the fear that the device might malfunction.

Situated Structure for Helen

The experience of living with an AICD includes events leading up the implantation and events during hospitalization. The participant is aware of the device on a continual basis and modifies attire to accomodate the device.

Support is primarily from family members and friends who pray for Helen. Understanding of the device by others is important to Helen,

especially when she considers a shock might affect some one else. She is aware of her uniqueness. Her regard for others is also conveyed in her recent concern about driving since the last shock. Fear of hurting someone while driving has revived the driving issue for Helen.

Trust in the physicians is evident in Helen's experience in the decision to have the implant, and in information-seeking behaviors that have continued post implant. Although she did not perceive a choice in the decision of having the AICD, trust in the device is dubious. She has concerns that the device may malfunction.

Ian

Ian is a 71-year-old Caucasian male who has had an AICD for 5 years and 4 months. Ian is an insurance broker, who continues to work, and leads a very active life. Ian has a 16-year cardiac history that began with a myocardial infarction. He had no residual effects from the infarction and no symptoms until an episode of sudden cardiac death. Sudden cardiac death and a second myocardial infarction prompted the implantation of the AICD. A new device was put in five years and two months after the first one, just two months before the interview. He has experienced a total of nine shocks, but none in the last two years.

When asked about the AICD, Ian creates the context for an explanation of the device. The context is immersed in his cardiac history. The device is not separate from his cardiac condition. This theme emerges in conversation that illustrate other themes as well.

The AICD gives Ian a sense of security. "In fact, it gives me a feeling of security knowing that I'm less likely to die from cardiac arrest than anybody, any age, really, who doesn't have an AICD." The sense of security is extreme, as Ian projects absolute protection. In discussing the decision to have the defibrillator, he illustrates his security with the device as he mentions, "I needed the defibrillator because I consider that it saved my life at least nine times since I've had it." Later he refers to the sense of security provided by the device as he states, "I just know it's there and feel secure in knowing that if I go into cardiac arrest, it's there to do the job." He thinks he is immune to cardiac arrest because of the device. "It's a comfortable feeling to know that I may die of a lot of other things, but I don't think I'm ever going to die from a cardiac arrest."

Ian's experience of living with the AICD is cradled in his sense of control. Ian has control over his health, his body, and his perception of the device. Ian states, "I don't let it bother me at all. I pace myself. I don't overdo it. I try to eat right. Still need to lose some weight. But as far as

having the unit, I don't let it interfere with anything I do." Control even underpins some of Ian's shock experiences. Of one shock in particular Ian concludes, "I'm sure I brought that one on myself, because all the many, many years I always finish my shower with a cold shower. I just feel better and I just forgot. I took a cold shower and evidently that was enough to stimulate my heart rate and it went off." When talking in generalities about the shock experiences, Ian's potential control over the situation is evident. "So most of the times it had gone off had been when I either overdid it physically, or had maybe a little unusual emotional stress." Ian interprets his experiences in a very linear cause and effect mode. This allows Ian to exert control over the cause. When he does not exert his capacity to handle a situation of stress or when he overexerts himself, shocks that could have been prevented occur. "Every time it has gone off, I could sort of look back and kind of get a feeling for what problem may have caused it, tired or overdoing it, not eating properly, and **letting** my heart get out of rhythm and whack, because of improper eating, or stress."

Ian has identified stress as a factor in his life, and has taken measures to control the stress in his life. He correlates stress to his cardiac problem, but focuses on the control he has over stress. "I've learned to control that. I've learned that the concerns I had in the past were not necessary because I've

always made good decisions, and I still have clients that call me and thank me.

...So, I know that a lot of my worries and stresses **back then** were unnecessary."

Sudden cardiac death and the sequela during his last hospitalization robbed Ian of personal control and the decision to have the implant. "They decided that while I was at the hospital there." Later he again mentions, "When **they** decided to do that, they had counselors talk to me, doctors talked to me, showed you a video. My wife was involved in all these interviews. I said, 'Well, if that's what I need to do, let's do it.' I didn't know anything about it." It was Ian's wife who agreed and understood. Even after counseling, videos, and interviews, Ian "didn't know anything about it." In deciding to have the device, Ian relinquished control to the physician's and his wife.

Ian lived with the device for three years before understanding the device and its function. Understanding about the device was a turning point for Ian in his acceptance and comfort. This significance of this is captured in Ian's own words:

And up until the last time it went off, my concern was that it must be getting worse you, know. My heart must be deteriorating, and I really became concerned about that until I went to see Dr. (name). And that

was the first time that he really took a long time talking to me. My wife was with me. Then he explained to me, you know, what the defibrillator is and why I have a defibrillator, and that was the first time it really got through to me about irregular heart rate or cardiac arrest. They say they don't really know what causes it, and they say they don't really have a cure for irregular heart rate except, you know, keep it in control with medication. And the fact that my defibrillator discharged did not necessarily mean that I was deteriorating or getting worse. It was just that's what I have. And the purpose for the defibrillator is to keep me from dropping dead with cardiac arrest. And that made me feel a lot better since then, you know. I've improved steadily and that was probably one of the turning points in making me feel better. Because I began to understand, you know, what I had and that I had no reason to be overly concerned about it.

This meaning unit describes a turning point in Ian's experience of living with the AICD. It was when a health care provider "took a long time" with Ian to explain what was happening and what it meant physiologically. In the understanding, Ian found that life with the AICD improved. The physician who explained the device to Ian was not the same physician who had

implanted the device, but he was the same physician Ian had been seeing regularly over three years for follow-up.

This meaning unit also suggests a trajectory, or story in the acceptance of the device. It is important to note that information about the device was given to Ian at the onset, but his understanding and comfort with the device did not occur until three years after the implantation. The notion of a story and the meshing of the device with the underlying cardiac condition is evident throughout the interview as Ian states, "Well, initially I thought that I was not ever going to be back, you know, to being myself and living a normal life."

When he initially had the device, Ian explains:

I was concerned. You knew it was there. You could see it and it stuck out, but the mental aspect of it at first was, well, you know, I've got a serious condition and I had always been very active and wasn't ready, you know to change my lifestyle all that much. But plugging away at it over three or four years, in fact, I feel better than I did before I had the cardiac arrest.

Ian identifies two other turning points in the trajectory; alterations in activities that he perceived as helpful. These were things that were within Ian's control. Ian reflects, "So I'd say there are three turning points, having a good conversation with my doctor and understanding the situation, going to

cardiac rehab, and eating properly and taking vitamins are the things I think helped me more than anything else." The first is directly related to the device; the second two are more closely related to the cardiac condition. As the condition is not separate from the device, it is a part of Ian's experience.

Going to support group meetings has meaning for Ian. He enjoys being around the people in the group, although he sees himself as different from them. Of the support group meetings Ian explains:

Just between you and me, it's made me feel great because I hear all these people who have problems and feel bad, and I haven't had any problems. I've been fortunate. I don't (pause), it makes me feel good to go to the meetings to realize that I think I'm a whole lot better off than a lot of people that come to the meetings.

Ian experiences distinction when he is among support group members, not when he is around persons without an AICD. When asked if people treat him differently, Ian replies, "I don't think so. Cause there are an awful lot of people that I know that don't know that I have a defibrillator. Cause I don't make a point to advertise it. It's not necessary, I don't think." His family treats him differently, and when he talks about how his family treats him, his language switches from first person to second person. "Naturally my family, my wife, and my family, they sort of get the feeling that you're an invalid,

you know, and want to do this for **you** and want to do that for **you**. My wife still hasn't completely gotten over that."

Ian's wife seems to be a reminder of his illness, yet a vehicle for denial. He mentioned his wife in the decision making process. He mentioned the way his wife treats him in a manner that is overprotective. Early in the interview he offers, "My wife probably has more concerns, still more concerns, than I do." Ian's experience of living with the AICD is enshrined in avoidance. He addresses his wife's concern about his health and the device rather than his own. When asked about concern surrounding the shocks, he replies, "Probably more to my wife than it was for me." He also does not "advertise" the device, and he speaks highly of the new device because it is better hidden in his body than the old one. "You can't see it unless you know, and that's a big improvement over what it was before."

Ian does exhibit gratitude for the device. "I am thankful that such a device is available, because it's done the job." He describes the AICD as a "piece of machinery there to do miracles for you when you need it, if you need it." He mentions being thankful for the device several times in the interview. His gratitude prompts his willingness to talk with people who are candidates for the device to talk to them about the device.

Gratitude consists of both general gratitude and directed gratitude.

Gratitude is directed to "the Lord" for blessing him with "good healing the first three years." On another occasion he mentions, "The good Lord blessed me." He never elaborates on his thankfulness or ideas about the Lord's interventions.

The shock experience for Ian brings his being and his heart into cadence. As Ian describes it:

Well, you've seen people get popped with the defibrillators haven't you? That's exactly what it feels like. I mean it just, you know, kind of lifts you up. It sounds like a bomb went off in your head. Of course you can't hear it on the outside, but to you it felt like a bomb went off. It really gives you a jolt and almost pops your neck, you know. But then immediately as soon as the shock is over in my case, I've always felt great.

Because the shock has been so sudden and he has experienced no repercussions, Ian feels it is safe from him to drive. He mentions the doctor is a "real strong advocate of absolutely not driving." But he goes on to explain, "In my situation there hasn't been any lag time, you know, it was just like that. And in a split second it is over. So I haven't had any sensations of getting to the point where I lose control, or get to the point of passing out."

Because he is an exception to the rationale presented by the physician, he is an exception to the recommendation. As Ian puts it, "I don't have any concern about getting in my car and driving. Not at all."

Ian has altered the way he dresses as a result of the device. He now uses suspenders instead of a belt, because the belt is at the level of the AICD. It has been a minor adjustment for Ian.

Emerging Themes

1. The experience of living with an AICD cannot be separated from the underlying cardiac indications for the device. The device serves as a reminder of a compromised heart and sudden death.
2. Accommodating the device is a trajectory that is impacted by understanding the purpose and actions of the device. It is erroneous to assume that leaning and understanding have taken place with consent to have the device implanted.
3. Three years of living with the device and then sudden understanding was a turning point in the acceptance of the device.
4. The decision to have the device was in the hands of others, including physicians and wife.
5. The wife serves as reminder of the cardiac condition, and the AICD.

6. Support groups are helpful, in that they provide comparison cases that result in feelings of being fortunate and better off than others.
7. The device offers a great deal of security. The security affords immunity from cardiac arrest.
8. Control is a major consideration. There is a notion of cause and effect in that there are activities that activate the device over which persons with AICDs have control. Activities such as stress reduction, diet, and taking vitamins improve health state.
9. Ian expresses a generalized sense of gratitude for the device and to the device.
10. Directed gratitude to the Lord for health and well-being.
11. Exception to physician recommendations when rationale for recommendation is not applicable to the case, especially when in conflict with sense of control, case example driving.
12. Moderate change in attire is necessary to accommodate the device.
13. The shock experience is rejuvenating and results in feeling better.

Situated Structure for Ian

The experience of living with an AICD is immersed in the Ian's cardiac history and cannot be separated from the underlying cardiac condition for the

which the device is indicated. Acceptance of the device takes place over time and is influenced by understanding the purposes and actions of the device.

Consent to have the device placed does not assure comprehension necessary to live with the device on a day-to-day basis. Education should be ongoing, as there is much that happens when the device is initially implanted. Instruction about the device at the beginning requires reinforcement and assessment of readiness. Understanding is a key to adjusting to the device and living most fully with the device.

The decision to have the device put in was primarily in the hands of others. Physicians were trusted, and the Ian's wife was instrumental in the decision. Ian's wife serves as a reminder of all that he has been through and as a reminder of the AICD.

Ian is different from other persons with AICDs in the support group. This difference is a positive facet, as the well-being of the people in the support group serves as a gauge of well-being that Ian has surpassed. Comparing his case to those of members of the support group for persons with AICDs, he believes he experiences superior quality of life. He expresses feelings of gratitude for the peerless quality of life. The gratitude is a combination of general gratitude for his well-being and gratitude to "the Lord"

for his well-being. It is a combination of both directed and non-directed gratitude for having survived his cardiac condition and for his present quality of life.

The device affords a great deal of general security. It upholds immunity to subsequent cardiac arrests for cardiac patients. It does not impact daily activities, although moderate change in clothing was effected to accommodate the first device's presence.

Control and autonomy are major considerations in living with an AICD. There is a linear cause and effect relationship between discharge from the device and behaviors of the individual. There are activities that cause the device to discharge, and there are general activities that can be done to improve one's health state. Activities such as stress reduction, taking vitamins, and eating a proper diet improve one's health state. The shock experience rejuvenates the body and improves the way one feels.

Exceptions to physician recommendations are acceptable, especially when the rationale for the recommendation is not considered to be applicable. This is especially true when the recommendations restrict control and autonomy, such as in the case of driving. Although awareness of the recommendation exists, the argument for nonobservance is forceful.

Jill

Jill, the tenth subject, is a 57-year-old female who has a five-year history of cardiac problems that began with a myocardial infarction. She is the manager of a store in an urban area, and leads a very active life. Jill has had an AICD for three years. An AICD was suggested as a treatment option for her five years ago, but Jill refused to have an AICD. While being hospitalized for a myocardial infarction, she overheard physicians discussing another patient whose AICD did not work and who died. The physician's conversations and obvious quandary over the failure of the device were instrumental in Jill's decision not to have an AICD. Jill, who had not experienced sudden cardiac death, chose medical management with anti-arrhythmic drugs. After 18 months on anti-arrhythmic drugs, which "just about killed" Jill, she opted for the AICD. Jill has experienced three episodes of shocks; one episode involved a series of four shocks, one right after another. She had the device for a year before experiencing a shock, and had not experienced a shock in the last five months.

Jill does not separate her cardiac problems from the AICD. When asked about living with the AICD, she narrates circumstances of her cardiac history 18 months before the device was implanted. She prefaces the interview with the statement that "I try to pretend that I don't have it, to tell

you the truth." The device is a treatment for a problem that Jill would rather not think about, so she tries not to think about the device.

The decision to have the AICD was an agonizing one for Jill. Having overheard the conversation among the physicians about the patient with an AICD who had died because her AICD did not work, she elected to have her arrhythmia problem treated medically. This greatly diminished Jill's quality of life. Her medical history is important as this was the impetus for the decision to have the AICD. As Jill explains about the medications she was on, "They gave me medication and I was on that for 18 months and it just about killed me. Literally, I mean that was the worst experience because I felt terrible all of the time. I had sort of muscle spasms. I couldn't think." Of the pills she was on, Jill later recounts, "I was happy to flush them down the toilet."

A source of conflict for Jill in the decision was the driving issue. This would be a loss of independence for Jill, as working is important to her. Jill discloses the situation when the physician talked to her about the device:

So I agreed to do it and the worst thing was, I think, that my surgeon came in and told me that when I had this thing in that I would never be able to drive again. So, I'm a single person and I support myself, and it was very important to me to continue to work if I could. I just thought, "Oh my gosh! What am I going to do now?"

Jill relied on her family to take her places and experienced a loss of independence. She says her children "took turns bringing me to work; taking me home. They didn't like it much, but they did it." The independence and driving issue resurfaces later. Jill talks about not wanting to be an invalid or incapacitated and then plainly states, "My independence is very valuable to me, yes. However I have to be careful when I say that, too, because I used to say it all the time. You know, anything can happen to me, just don't take my car away from me because I just need my car." Being careful conveys a delicate balance in Jill's life.

The device provides Jill with a sense of security meshed with skepticism. This is true of several aspects of Jill's being, as she deals with trust issues. Of the device Jill states, "It gives a sort of sense of security. Probably a false sense, but it does give me that, so therefore you're not real concerned about it." When discussing physicians who handled her case Jill explains:

I don't feel like actually that my care was handled very well at (large urban hospital) in the first place, so I'd kind of lost a little confidence in the physicians, and that's bad for me because I have a great high regard for physicians and their job and what they do. I'm pretty trusting of them, probably too trusting. But I feel like there was some

things that could have been done differently and better and I probably might not have these problems, but on the other hand, what can I say, this may just have been my lot in life.

Jill's experience of living with an AICD is undergirded by her sense of a spiritual in which she has placed her trust. "Don't pray for something or the Lord will give it to you." She makes numerous references to "the Lord," to whom she attributes control over her being. This gives her solace. "I guess if the Lord's willing, I'll live through it. If He isn't, I won't." This is brought up throughout the interview as Jill states, "That's why I say it's only by the grace of God I am here, because I mean there is something He wants me to do." She also shows trust in her statement related to her having to rely on others initially, "But that was I think by the help of the Lord. He just gives you, that's what he gives you, is the comfort that you need so." The Lord has a plan for Jill, and that explains her existence after all she has been through.

Jill indicates that there is a process of adapting to the presence of the device that transpires over time. In Jill's words: "It's a large unit, and it's uncomfortable where they put it. But you kind of get used to anything, you know, after a while." A turning point occurred when Jill was able to drive with physician consent. Her electrophysiology studies indicated that she would

most likely be able to identify when "an attack was coming on." She states that at that point, "I guess I began to feel more normal."

Having the AICD was instrumental in Jill's contemplation of life and death. As recounted by Jill, "But then when I had my heart attack and then I had the AICD, I spent three months at home not doing anything, just reading and thinking and coming to terms with I guess life and death." Choosing to have the AICD was a choice of quality life. "It's just the odds are a little more against me than others."

The support group is not an activity in which Jill is involved. She explains that it conflicts with her work schedule, but then adds:

And I guess another reason I don't want to do that is I get letters from them and then they'll say in them 'We are sympathizing with the family of those who are not with us anymore.' And I don't think anyone who has a potential death hanging over their head really wants to see that!"

Jill's family and a physician friend have been most supportive through the process of living with the AICD. She describes the assistance her children gave her in getting around when her driving was restricted. Her son "calls me every night, because I'll probably be laying in here stiff as a board for three or four days before you all ever know I'm gone." Her friend who is a physician gives her comfort:

Because he tells me to call him any time, night or day, if I call him at home....It's not like I'm going to some doctor that doesn't know me, that doesn't, that I'm just another statistic. And which is the way I am with my other doctors, you know, the surgeon and the cardiovascular, I mean cardiologist, I'm just another patient. But with (name) I'm a special patient, you know, because we're friends. So that gives me comfort, because I know I can call him. I know he'll be there or make sure I have the **proper care**.

Jill uses humor and avoidance to bridge herself to others who do not have the device, and to maintain a sense of normalcy. "I never talk about it other than jokingly with some of the girls downstairs or something. I mean, I don't ever. Like I said, I just kind of pretend it isn't there so I don't ever talk about it." Yet on the other hand she relates that she tells her boss, "Now wait a minute, you can't fuss at me because you don't want this thing to go off." She will tell her boss, "Now you leave me alone because this thing might go off and you wouldn't like that." Humor connects her to others, but at the same time reveals that her willingness to be aware of the device fluctuates. If it is a source of convenience in getting out of a hard situation, humor is employed. In situations where she feels she will be treated differently because of the device, such as when she doesn't feel well and others suggest she go

home, she replies, "No, I'm not going home, if I am going to die, I want to be around people. If I go home I'm going to be at home by myself. So if I'm going to die, I want you all right here with me." On occasions with her coworkers she also remarks, "Now look, if you find me on a staircase or something, don't stop working. Don't stop working, just push me over to the side till the ambulance can come and get me. Just keep on working." Humor also helps Jill come to terms with death.

Jill has also changed the style of clothes she wears to accommodate the device. She explains that it is uncomfortable to have clothes that are snug in the waist. "That's why I wear clothes that kind of hang out, and that's a problem, is finding clothes." Certain activities such as leaning over a desk remind Jill of the device.

Jill expresses some concern about having to have the device changed, but evident in this dread is the assumption that she will continue to live. As Jill states, "I'm assuming that it will have to be changed in another couple of years. I've been sort of dreading that, but it's supposed to last five years, and I've had it three." Jill postulates in this statement that she will be alive, in spite of the earlier indications of the "odds against" her. An unrealized sense of hope is evident.

Emerging Themes

1. The AICD is not and cannot be separated from her cardiac history and hospital experiences related to her cardiac history.
2. The decision to have the AICD was difficult and had been postponed. Ultimately there was no choice compatible with life, and quality of life, as the medication regimen was unacceptable. The decision was doubtlessly influenced by the conversation of the physicians about the patient who died because her AICD did not work.
3. The initial suspension of driving resulted in a loss of independence that necessitated reliance on others and changes in personal constitution, as independence is highly valued. The return of driving privileges restored the sense of independence, but the loss of independence is ever threatening.
4. Adapting to the AICD is a dynamic process that takes place over time. It is not an immediate condition, and since it cannot be separated from the experience of illness it must be considered with the illness.
5. Humor and avoidance are two factors that mediate the adaptation process in relation to others and in the awareness of death.
6. There are forces in Jill's life that provide a balance for her. The presence of "the Lord" gives Jill comfort and hope in the presence of death, as the plan "the Lord" has for her life transcends death.

7. The device provides Jill with an ambivalent sense of security.
8. Although dreading the changing of the device in two years, Jill assumes that she will be alive to have that done. An unconscious sense of being and hope is manifest in her dread.
9. Balance is also seen in the presence of her physician friend who gives her comfort. Physicians who manage her care, she does not trust.
10. The support group notion is perceived as shifting the balance as it is a reminder of death.
11. Certain activities, such as leaning, bring the device to Jill's immediate awareness. However other than driving, activities have not been limited by the device.
12. Alteration in the way Jill dresses occurred as the result of the device implant.
13. Support from family and friends is essential to Jill.

Situated Structure for Jill

The AICD is not a separate entity from the cardiac problems. The AICD as a treatment for underlying cardiac problems serves as a reminder of the cardiac problem and awareness of looming death. Adjusting to having the AICD is a dynamic process that takes place over time and is not immediate.

There is fluctuation in the awareness and acceptance of the device, and since it is not a entity separate from the underlying cardiac problems, can only be considered a portion of the total experience surrounding the cardiac condition.

Jill continually experiences an awareness of life and death. The awareness of life and death is indicative of one of several fluctuating balances that occurs. Trust in a spiritual being, and a notion of a plan for Jill's life give her a sense of hope and purpose that balances the experiences she has had with illness and her cognizance of death. Becoming a part of a support group, in which people with the device die, is a weight in the direction of death. Communication from the support group upsets the balance and makes her think of death, and her own mortality. Support is essential and is sought among family members and friends and not persons with a AICDs.

An imbalance between independence and dependence emerged when driving restrictions were recommended. Alterations in previous transportation modes resulted in dependence on others and were difficult. Independence was restored with driving, but only a temporary sense, as the thoughts of not being able to drive continue to surface. She knows that nothing is permanent.

A conflict of trust and mistrust is evident in Jill's interactions with health care professionals and health care institutions. A physician that is known on a non-professional basis as a friend, provides comfort and

appropriate attention. Physicians who have managed Jill's case were ineffective in providing the care and concern Jill needed. Mistrust was planted before the having the device in the overheard conversation of another patient's demise. There is a feeling security in having the device. It is considered a "false sense" of security, meaning the feeling exists, even if rationale, or logic to explain the feeling does not. The feeling of security prevails.

The process of living with the device is mediated by humor and avoiding thinking about the device. Refusal to think about the device annuls its existence; not mentioning it to others annuls its existence. Yet, humor reconciles the presence of the device to people with whom Jill comes in contact. Humor is accented with themes of death. The humor reveals an underlying fear of the device going off, and fear of death. It is also employed at times for convenience in situations where Jill's variation from others is advantageous.

The choice to have the AICD was a choice to live a meaningful life that was diminished by other treatments for the underlying cardiac arrhythmia. The device contributes to a dubious sense of security, somewhat influenced by an overheard conversation about a patient who died because her AICD did not work.

Certain activities, such as leaning into an object or on an object are reminders of the device. Activities have not been attributed as limiting by the device itself, but rather the underlying cardiac problem. The device has resulted in a change of apparel style, so that clothing is not tight over the waist at the area of the device.

The dread of having to have the device changed in two years establishes an underlying assumption that Jill will be alive in two years to have the device changed. Although expressed as dread, the assumption is laden with a unrecognized hope and auspicious sense of being in spite of fears of death.

Ken

Ken is a 72-year-old man who has had an AICD for 2 years and 4 months. The AICD was implanted following a second episode of sudden cardiac death. Ken's only shock experience occurred 14 months after the implant and was the result of a malfunction of the device. The device shocked Ken 70 times before he could reach personnel knowledgeable about the device to disable the device. Ken lives alone in an urban neighborhood. He has two grown children one living several hundred miles away, and one in a near

suburban town. Ken is widowed and lost his wife a year and a half ago to a rapid onset of cancer. He is self-employed and works out of his home.

Ken's experience of living with an AICD is most immediately dominated by the malfunction of the device, and his anger surrounding the malfunction and its sequela. Anger is not exclusively directed at the device, but also toward health care professions who will not answer questions about the malfunction. When asked about the experience of living with an AICD, Ken immediately relates the story of the malfunction and indicates:

I was angry and disappointed. I mean it was bad enough that it happened, and that really scared me and made me angry, but the way people wouldn't talk to me about it was something else. I mean I kept thinking that they thought I was going to sue them or something. I just wanted to know what happened. In fact, when I saw my doctor again after that time, I asked him what happened and he just didn't seem concerned at all. Then, well, he said something about having to check my record, but he never did....It pissed me off!

The malfunction experience impacts Ken's experience of the device and cultivates some issues of trust. "I need the device, and I'm thankful that they were invented, but I just wish mine hadn't gone off on me. I just hope it

works when it's supposed to, you know. If it works when it isn't supposed to, what does that mean for when it is supposed to?"

This trust conflict is balanced by the initial feelings and choice to have it put in. Ken's awareness of tachycardia and his awareness of the distance between his home and the hospital were part of his decision. "You know that with tachycardia, you don't have but twenty to thirty minutes to reach the hospital before you die. So when the doctors recommended it, I thought I should have it put in....I decided to have it put in even though I live close to the hospital." The initial trust in the physician's recommendations are clear, and in spite of the malfunction the and the presence of mistrust, there still exists trust. "If you need it, you need it. There is no choice. I haven't needed mine, yet anyway, but I feel like if I ever do need it well, I have to have it and that's why it's there. I need to have it." Ken identifies a sense of security with the device, but again the malfunction experience is pervasive as he indicates, "With all of the trouble I had, I shouldn't have even had it installed, I guess." Ken goes on to identify that he "needs" it. There remains much anger, concern, and ambivalence.

Ken is searching for some understanding about the possible causes of the malfunction from the medical community. He reiterates, "I am not out to sue anybody, I just want some answers and it seems nobody wants to tell

anybody anything." He describes a rare appearance for him at a support group meeting in which he continued his search for some understanding:

Well this doctor had just given a speech. It was good. Then there was a question and answer period about everything. I felt like I wanted to know why this thing had gone off so many times, so I just stood up there and said, "What makes this thing go off 70 times in a row like mine did?" He just told me that was very unusual and has almost never happened. Even so, it is something when it's you that it happens to!

Support for Ken comes primarily from a friend who has a heart condition, but no AICD. His friend "Calls everyday, sometimes more than once or twice a day, just to shoot the breeze and to see how I am." Support does not come from the support group meetings, although Ken has attended. He indicates, "I don't need it. Some of them do, and I understand that, I just don't need it. I don't care to talk about it all of the time." At the end of the interview, Ken indicated to the researcher, "You know, it helps to talk about it. I mean really, I don't talk about it a lot, and since this thing happens nobody wants to talk to me." Talking about the device to someone who will listen is helpful to Ken, and this is "support."

Ken indicates a trajectory of accommodating the device. "As far as real discomfort, I would have to say it is minimal **now**." The malfunction event has made a difference in this trajectory, but it is obvious that Ken is searching for some meaning to this event, or at least on understanding of why this happened. His efforts to seek answers and understanding are experienced with suspicion toward health care professionals.

Ken indicates that the device is in his immediate awareness all of the time because of its size. "Just look at it, it's bulky!" He indicates that he stands a lot more at work since the device was put in because the bulk of the device makes sitting uncomfortable.

Emerging Themes

1. Anger and disappointment are associated with the malfunction of the device.
2. Anger is the result of failed communication attempts by Ken to obtain understanding of the malfunction from health care professionals who are suspicious of Ken's intentions.
3. There is a dilemma of trust and mistrust. Ken trusts the device and needs the device, but at the same time is distrustful of the device because of the malfunction event.

4. The malfunction has interrupted Ken's trajectory of acceptance, and his attempts for deeper understanding have been thwarted by suspicious health care professionals.
5. The choice to have the AICD was affirmation of trust in physicians, and an affirmation of life. Life is affirmed by the idea that there was "no choice" about having an AICD.
6. Support comes from a friend who calls frequently. Support groups are not helpful.
7. The device is in Ken's continual awareness because of the bulk of the device.
8. Modification in daily activities is associated with the device to be more comfortable with the device, such as standing at work instead of sitting.

Situated Structure for Ken

Ken's experience of living with an AICD is dominated by a malfunction of the device in which Ken received 70 shocks. During the episode even after reaching the hospital it could not be turned off until special personnel were there to do it. Anger and disappointment are the emotions that are associated with incident and surrounding events. Since the incident, Ken has sought to understand the cause of the incident from health care

professionals. He experiences health care professionals as being suspicious of his motives for questioning the event. This has resulted in no communication from the health care community, and more anger by Ken.

The choice to have the AICD was an affirmation of life for Ken, and an affirmation of his trust in physician's, the device, and the health care system. Affirmation of life was evident from the notion that there was no choice in the matter of having the implant.

Support groups for persons with AICDs are not helpful for Ken. Support is rendered by a friend who calls frequently.

The bulk of the device makes the device in the recipient's immediate awareness. He modifies activities at work to accomodate the bulk of device.

Lee

Lee is a 60-year-old Caucasian male who has had an AICD for 37 months. Lee has had two shock experiences, one outside of the hospital, and one while in the hospital. The first shock experience occurred after the device had been implanted 26 months, and due to intervention from emergency medical technicians wound up being a series of 5 shocks. Lee experienced a myocardial infarction 13 years earlier, and then another myocardial infarction three years ago. Although he did not experience sudden death, three years ago

he was externally cardioverted to correct as sustained arrhythmia, then had the AICD implanted. Lee continues to work as a construction worker, and continues to be licensed to operate heavy equipment. He lives in a suburban area with his wife and fourteen year old son. He has one grown son still living, and two that have died due to substance abuse.

Lee describes the sensation of ventricular tachycardia that he experienced prior to having the AICD, after the first heart attack. When he describes the heart beating fast he mentions, " I just feel for some reason it put itself back in, gets so fast I guess it just goes back in. But I know several times it would get that way and you'd just feel, just get dizzy and feel like all of the life is draining out of you." The dysrhythmia "drained" the life out of Lee, with the feelings of weakness and dizziness.

Lee's experience of living with the AICD is one in which he tries to avoid thinking about the device, or circumstances surrounding the device. When asked on a day to day basis when he thinks about the device, he responds, "I don't think about it. I don't think about it period. I make it a point not to. I make it a point not to." He indicates that, "The only time I ever think about it and I'll get up if something like that, I see something like that on T.V. But I just don't think about it. Don't think about it."

When discussing support group meetings, Lee's desire to keep from thinking about the device surfaces:

And I really don't enjoy talking about it either, you know. Maybe one reason, I never thought about it, but I don't care about going to support groups any more than I do. Because you know, as long as I can stay busy, or something, well, I forget I've got the thing.

Lee is not treated differently by people he knows as a result of having the device. He talks about his son who, "doesn't treat me any different because I've got it. I mean he don't. Normal 13 year-old boy. He'll just walk up and slap at me or whatever and we play. I let him know it's there, and he don't hit there. But he don't slack off any on account of it." Lee indicates that most other people doesn't know he has it, so they do not treat him differently. Lee does feel different and separate from people he has met in the support group setting. This difference, and uniqueness is evident in Lee's description of the group:

Most of them have had a lot more trouble with them than I do. Most of them goes off more. In fact, I think I'm the only one that goes that still works, the rest of them is all disability or old enough to retire, one or the other. But I don't think there is anybody else there that even works.

There is an advantage to the AICD for Lee over other treatment modalities. This advantage was instrumental in his choice to have the AICD. The choice seemed a forced choice in that the AICD was better for Lee than taking medications. As Lee recommends, "At least you forget to take medicine sometimes. And you don't have any side effects from this until it goes off, you know, there are no side effects or nothing from it. I'd rather have it than to have to take medicine." Trust in the device is embedded in Lee's comparison of the device to medication in that "you never know when you go to get some medicine that it may be the wrong thing. That's happened a lot here in the last few years."

Lee experienced conflict in the decision to have the device, but then decided there was not much choice. "I never did like nothing artificial really. But if it something that will keep me going, well, no, it wasn't a hard decision at all." Lee's wife reminded him and the physicians that he "was not going to stay close by," so implantation of the device was conducive to Lee's lifestyle. Lee is more independent and autonomous because of the device.

Lee also experienced a process of adjustment to the device. His process was more physical adaptation than emotional or psychological. Lee states, "It was bothersome. It took me a couple of months to get to where it wasn't sore if you made a sudden move or something." This was an

acceptable trade off because, "I've felt better about myself since I've had it and known what it was because so many times before I got it, you know, I'd feel that feeling, it just felt like I was dying." The device prevents Lee from experiencing a feeling, "like you're dying, you just feel like all of the life's gone out of you," and the feeling that, "all the life's draining out of you." Again embedded in the function of the device is a sense of security in that it prevents Lee from feeling like he's dying.

Awareness of the device is apparent with certain movements and when it bumps into other objects. Driving with the device was also brought up by Lee. He is sure that he would remain in control of a vehicle, and his pragmatism emerged when this recommendation was made. When told by his physician he would not be able to drive, Lee's response was:

Man, I got a problem and you may as well just show me where the food stamp and welfare office is if you take my driving away from me, because I can't make it....You know, the roads are full of drunks out there and they don't know they got a problem.

When asked about fear of shocks, Lee is ambivalent and equates fear of shock with fear of death. "I guess when I had the first one, I made my life right and I was prepared to die whenever it happens, and still am. I'm not saying there's no fear, I guess there's always fear, but I don't dwell on it, and

I don't have fear." Fear is associated with death, fear of shock is associated with fear of death, such that, if it is not thought about, it does not exist.

Lee experienced his first shock a little over two years after the implantation. Lee indicates that the morning of the shock, he had been feeling dizzy and weak. "Well I felt good just as soon as it was over with. Of course I was kind of scared, no doubt, because I didn't remember what to do. You know, wondering if it was going to go off again or what." So even though there is a sense of 'feeling good' there is apprehension about being shocked again.

Lee experienced unnecessary shocks due to lack of knowledge about the device by emergency medical technicians. He recounts the episode when his device went off and he went to an ambulance service, as he was in a rural area at the time. Lee narrates:

One of the ambulance attendants came out and began checking me, you know, and he said I needed to get to the hospital now. I told him, "No, they said to wait." He said "No. We need to get you there now." So they decided to go on. Well, just about the time we left, the doctor called and said, "No, don't do anything. Just leave him there." But they decided to bring me anyway. Well, on the way, they gave me a shot of something and it set, of course. I didn't know what was

going on, it set it off twice. Well, they gave me another shot and when they gave me the other shot it set it off the other three times. So when we got to the, I was okay by the time we got to the hospital. And when I go there the doctor, he just told me, he said, "Well, there wasn't any need in you getting shocked those other times. That first time had already done what it was suppose to do. They gave you the wrong kind of medicine. I told them not to." But, evidently they thought they knew more than the doctors did I guess.

Dread of having the device changed is mentioned by Lee. This dread is something Lee says, "I don't dwell on that either though." If dread of something is present that will not take place for a while, there is an underlying element of hope. Hope is conveyed by Lee when he speaks of his son. "I guess he's one of the biggest motivators that I've got, that I want to see him grown and through school, out of college, hopefully." So in dread, there is an element of hope; in his son, he finds a reason, as Lee says, "to go on."

Emerging Themes

1. There is a process of becoming used to the device. The process of adjustment is directed toward physical accommodation of the device in the body and soreness that accompanied the insertion of the device.

2. Psychological and emotion processes of adapting are constantly maintained by choosing not to think about the device, and refusing to be in situations such as support groups that function to acknowledge and discuss the device.
3. It was a difficult decision to have the device, rather to have to accommodate the device. The device conforms to the lifestyle better than medications. There was no choice to have to intervene.
4. Device eliminates feelings of death, or life being drained. Maintains equilibrium of feelings of life and death. Shock results in anticipation of next shock.
5. Fear of death.
6. The security of the device lies in its advantages over medical management. Medical management is subject to more variation than the device, including forgetting to take the medication, error in dosage and administration, and side effects of the medicine.
7. Being unique from other people with the an AICD due to age and working status, and fewer problems than others have with the device.
8. Family member, particularly son, is motivation for existence. Hope is embodied in relation to son as son's development provide goals and a gauge.

9. Autonomy and independence threatened by recommendation of physician in regard to not driving. Circumvents recommendation with rationalization and justification for driving.
10. Aware of device when it bumps another object.
11. Insidious awareness occurs in other activities and are mediated by redirecting thoughts and removing reminder.
12. Disappointment with and mismanagement by health care providers who do not understand the device. Mismanagement resulted in excessive activation of the device and four additional shocks.

Situated Structure for Lee

There is a process of adjusting to the physical impact of the device on the body, and a soreness that occurs for a while after the implantation. Psychological adjustment is not allowed as the presence of the device is annulled by conscious effort to avoid thinking about its existence. Lee avoids thinking about the device by talking about it, and not being around others who have the device who want to discuss the device. Also when aspects related to the device or the cardiac condition emerge, the stimulus is removed, or Lee removes himself from the stimulus. Immediate awareness occurs when device comes into contact with external objects, and is bumped.

The process of deciding to have the device was no choice, as it was more convenient than the alternative. The device eliminates the necessity to continually take medication, and eliminates side effects from the medications, and the possibility of receiving the wrong dose or medication. The device eliminates the active continual maintenance of health, which is compatible to the his preference not to think about his cardiac problems. A medication regimen would require more day to day thought than the device requires.

There is continual fear of death, although the strength of that fear fluctuates in consciousness. The notion of death accompanies thoughts of the device, such that to not think about the device, is to avoid thinking about death, although both occasionally come to immediate awareness. The device is a reminder of death, but at the same time eliminates the feelings of life being drained, or actual feelings of imminent death.

Family members, particularly son, provide a reason for living and a motivation to keep active. Son provides meaning to life, and provides goals and time gauge for existence. The son provides a sense of hope. Hope is also insidious in future dread of having the device changed. As this is a dread of futuristic events, there is an assumption that life will continue.

Treatment from other people is not different because of the device. The device does not separate him from other people. Separation and

uniqueness from others with the device is the result of lack of problems with the device, age, ability to work, and most recently identified as an arena where immediate awareness of the device transpires. The support group does not provide support; it serves as a reminder of the device, and does not allow opposition to existence of the device.

Dissatisfaction with the medical care system is exemplified by mismanagement of a situation involving the device. This dissatisfaction and mismanagement is the consequence of inadequate understanding of the device by medical personnel not directly involved with implanting the device. Lack of knowledge, resulting in mismanagement, was harmful to Lee and resulted in shocks that should not have occurred. This lack of knowledge evokes some skepticism about health care professionals and raises issues of trust.

Autonomy, independence, and overall quality of life would perish for Ken if driving was restricted, or eliminated. Autonomy, independence, quality of life are valuable and take precedence over recommendations from health care professionals, particularly when physician recommendations do not seem to be followed by other medical personnel. The recommendation is mutually exclusive to these values so the justification for not following the recommendation is logical, pragmatic, and necessary.

General Structure

A general statement or structure, according to Giorgi (1975), "leaves out the particulars of the specific situation and centers on those aspects...that emerged, which while not necessarily universal, are at least trans-situational or more than specific (p. 88)." The transformed meaning units have been presented as themes and have been synthesized and integrated at one level, as demonstrated by the situated structures for each subject. At this juncture a presentation of the general structure of the experience of living with an AICD is warranted. It is important to consider that "all transformed meaning units must be taken into account. The criterion would be that all of the meanings of the transformed meaning units are at least implicitly contained in the general description" (Giorgi, 1985, p. 19). This does not mean that each person experiences each and every meaning unit, but rather that each meaning unit is incorporated into the general structure of the experience. To assume that all meaning units are applicable to every subject would imply that the experience of living with an AICD is the same for everyone. This is incongruous to the philosophical underpinnings of the study, and it disregards the uniqueness of the individual as presented by the situated structures. Had this been the assumption of this study, one subject's description of the lived experience would have been adequate to describe everyone's experience of living with an

AICD. The point that is essential in this method is that the general structure of the lived experience is inclusive, in that it contains, at least implicitly, all of the themes that have been presented. It does not mean that the experience is identical for each subject, but it would follow that within the general structure that there would be aspects that each person who has an AICD could identify as part of their experience.

The dimensions of the general structure of the experience of living with an AICD will be identified, and an exemplar meaning unit will be presented to illustrate the dimension. To present every meaning unit in the study that supports the element would be redundant. The meaning units for each participant have been developed into themes. These themes have been developed into the dimensions of the general structure. The dimensions will then be presented as a conceptual model so that relationships among the dimensions are clear. The relationships among the dimensions identify the general structure of the experience of living with an AICD.

Description of the General Structure of Living with an AICD

The experience of living with an AICD was derived from interviews with twelve persons with AICDs. The context for the experience is found clearly in the union of the AICD with the total cardiac experience. The

general structure of the experience of living with an AICD can be found in seven dimensions in the context of cardiac problems. Those dimensions include:

1. A Story of Assimilation
2. Choice/ No Choice
3. Understanding
4. Support
5. Trust/ Absence of Trust
6. 7. Syzygy of Feelings
7. 8. Specialized actions related to having the device
8. 9. Symbolization of the Device and Its Action

Union of the AICD with the Cardiac Experience

Every subject incorporates descriptions of the cardiac experience that led to the implantation of the AICD into the experience of living with the AICD. The total cardiac experience provides the context for the lived experience. The AICD is a part of the whole cardiac experience that cannot be separated. When asked about living with an AICD, most subjects began with a cardiac history. Those who did not begin with a cardiac history wove cardiac experiences prior to the implantation into their experience of living

with an AICD. Each situated structure that has this as a constituent has an example of a meaning unit that supports this element. An example is Gail's response to the request to tell about living with an AICD

(GAIL) I don't live any differently now that I ever did. I don't really know what to tell you. I've had mine since 1990 and I don't believe they started even doing this much before 1988. I had mine, well, in January of 1990 I had the heart attack, and I had an aneurysm on the lower left ventricle, which Dr.(name) had to remove. And they did CPR on me, oh, gosh, I guess three or four times, and so they had to move up the surgery earlier than what they intended to get done. And of course, each time I blacked out,

Story of Assimilation

There is a process of assimilation of the device into one's overall being. This process is a dynamic evolution that is mediated by understanding and experience. The process may be characterized by directing energies to ignore the existence of the device, which is a form of assimilation. The process is particularistic to the each individual. Time is the ground of all experience in that it is in time that understanding and experiences occur that facilitate the process. The progression is not uniform. Experiences transform persons with AICDs; the meanings of those experiences are personal and vary from person to person. Similar experiences are interpreted differently and have personalized meanings. The other dimensions are subsumed in the story of assimilation. The meanings that the concepts have are in relation to one

another, within the story of assimilation, which is grounded in time, and in the context of the whole cardiac experience.

Eve (Experience as part of the process): But once it finally fired after 18 months, and we saw that it didn't do anything to me, you know, then it was a whole lot better. If we could have made it fire earlier, it would have been a lot easier to live with.

Choice/ No Choice

Choosing to have an AICD is an affirmation of life in the presence and awareness of death. Even when the choice is left to a family member due to incapacitation of the recipient, it is an affirmation of the values of life. To choose the AICD is to choose life over death. No choice is evident in the experience of some in order to live. For those who felt they had no choice, death was not a choice either. Because these people chose Life, they had no option to refuse the AICD. The dimension of choice/no choice is the actual starting point for the story of assimilation, it is initiated by this dimension. Subsumed in this dimension is general gratitude and gratitude for the device. The device provides a choice.

Gail: My husband just didn't expect me to live and Dr. (name) told him, "We're not doing this to keep her alive. We're doing this so she will live." And that's all it took! So if I wanted to live, I had to have the AICD.

Helen: I told her, I said, "Opal, it's just like me. We don't have a choice."

Eve: My mother is the cause of me having it put in. Because of what it would do to her. It's hard to lose a mate, or it's hard to lose your parents, but losing one of your children is the worst that can happen to you. I didn't think she could take it. I couldn't get her ready for it. So we had it put in.

Understanding

Understanding includes understanding that is personal understanding and understanding by others. Personal understanding through experiences, or education facilitate the story of assimilation. Understanding is sometimes blocked or postponed as each individual interprets experiences and understands the meanings of those experience differently. Lack of understanding by others affects the process. Sometimes humor is used to bridge the device to others, as others become incorporated into the process, and become a very important part of the process as evidenced in the concept of support.

Ian (Understanding as part of the process): And that made me feel a lot better and since then, you know, I've improved steadily and that was probably one of the turning points in making me feel better because I began to **understand**, you know, what I had and that I had no reason to be overly concerned about it.

Don (Others' understanding affects the story): Now the pastor of our church has been supportive. He **understands** about the AICD. Most people still don't understand about it.

Abe (Others' understanding affects the story): I began to realize that at first I was distancing myself from them instead of them from me. Abut fifty-fifty I think was the way it was. Some of them still, you know, hesitate to, well, they'll shake your hand, or something like that, they just don't want to be real close if something happens. Most of them have learned to accept it in areas where I go. Church and all that. I'm real pleased.

Ken (Lack of being understood affects the story): I am not out to sue anybody, I just want some answers, and it seems nobody wants to tell anybody anything.

Jill (Humor with others): I tease about it all the time.

Lee (Assimilation by choosing to ignore the device): I don't think about it. I don't think about it period. I make it a point not to.

Support

Support is an element of the general experience of living with an AICD. Support comes from assorted individuals and groups and the sources of support vary. However, support is a common thread among persons with AICDs. Some groups, such as formal organized support groups, are not sources of support for everyone. In some cases the formal organized support group is very helpful. Support comes in many different forms.

Eve: I wouldn't go to a support group for any reason, I don't think. I think that's for people who can't handle their own problems and try to lean on other people. I can handle my own problems. I have the Lord. I have my husband. I have my family.

Abe: Family support is the best support, and those support groups, the meetings we go to every month. That is the next thing.... You get together with everybody whose got these things, you know, and you get to talking about your experiences and they'll tell theirs. You can tell yours and you listen and learn. You find out that you're not the only one who's having the problems you know. It makes you feel good to know that there's just beaucoups of people who have these devices and have learned to live with them.

Ken: I have a friend who calls everyday, sometimes more than once or twice a day, just to shoot the breeze and see how I am.

Lee: I've got a 13 year old son, and I guess he's probably one of the biggest motivators that I've got...

Helen: I had a lot of people praying for me and that does the job.

Don: Lucky I have a supportive wife. She's stuck through it all.

Trust/ Absence of Trust

Trust is a common thread in living with an AICD. The objects of trust

vary with each individual, and the objects vary in time with each individual. People with AICDs exhibit trust in the device, health care personnel knowledgeable about the device, and the Lord. There are times when an absence of trust exists, or when trust and an absence of trust exist at the same time, very much like a syzygy that is discussed in detail as a dimension of the experience.

Carl (The device): ...It absolutely amazes me! I almost can't comprehend the thought that when my heart stops that this is going to kick in.

Helen: (The device) I don't take any pills now. Just rely on this.

Jill (The Lord): Don't pray for something because the Lord will give it to you.

Bob (Physicians and the device): **They** said, "If your heart gets to beating as fast as it did, you'll never make it through another one." So that stuck in my mind. "Put it in doc." It's just like having a doctor with me.

Fred (Physicians): I left everything up to the doctors.

Gail (Trust/ Absence of Trust) And he said the only thing we can do is go with the defibrillator if you will have one. And I said well, I'll take it because what else have I got that besides that, you know. The only thing I could think of what worries me a little bit about it, is what if it was to malfunction and start going off just like this, you know.

Ian (Trust/ Absence of Trust) I knew it was there and I knew it would do the job, but what if my heart gets so bad that a shock won't bring it back in line.

Syzygy of Feelings

The feelings of persons with AICD are found in syzygies. A syzygy is a term that is frequently found in astronomy that is used to describe conjunction and opposition of two celestial bodies. Kainz (1988) indicates that

a syzygy occurs when various opposites enter into a "dynamic unity-in-distinction where there is simultaneous conjunction of ideas which would not be permitted to cohabitate if the rules of ordinary logic and usage were followed" (p. 42). Conjunction and an appearance of opposition occur simultaneously and are a part of the whole. It is evident that the feelings conveyed by the persons with AICD can be viewed as syzygies. Whereas the emotions are not necessarily "opposite," they appear incongruous. By reviewing the situated structures for each participant, it can be seen that there are contradictory emotions present that are part of the whole. The emotions take on different forms and vary. Emotions readily identified in the various syzygies include depression and gratitude, freedom and restriction, security and doubt, fear and safety, comfort and annoyance, and feelings of being the same and different. This is not an exhaustive list, but it should demonstrate the existence of syzygies in persons living with AICDs. Syzygies emerge between understanding and trust/ absence of trust, and between understanding and support. Syzygies that emerge between understanding and support are typically related to connectedness and isolation. Again, understanding is personal understanding, and the understanding of others with whom the subjects encounter.

- KEN (Security & Doubt) If you need it, you need it. You have to have it. I haven't needed mine, yet anyway, but I feel like if I ever do need it, well, I have it and that's why it's there. I just hope it works when it's supposed to, you know. (From Trust/ Absence of Trust and Understanding)
- ABE (Freedom & Restriction) I just, what the heck! Do what I want to do. I vacation, go to ball games, all that good stuff. The main thing is just don't get out by yourself, I mean way out, cause there's always that possibility that something could go wrong. (From Trust/ Absence of Trust and Understanding)
- JILL (Security & Doubt) It gives sort of a sense of security. Probably **false** sense, but it does give me that, so therefore, you're not real concerned about it. (Trust/ Absence of Trust and Understanding)
- HELEN (Fear & Safety) I feel like I'm a little bit afraid if it was to go off about what would happen.... You feel a little bit safer. Or at least I do. The only thing that worries me a little bit about it, is what if it was to malfunction and start going off. That creeps into my mind every once in a while. (From Trust/ Absence of Trust and Understanding)
- HELEN (Similarity & Difference) I know I am the only one around that's got one. Yeah, it makes you feel different now in a sense of the word.... People don't treat me any differently. Probably most people don't even know I've got a defibrillator. We **still** eat out a lot; we go out and eat, and talk to people out like that, you know. (Connectedness and Isolation)
- GAIL (Similarity & Difference) I don't really live any different now that I ever did.... After four years people still think I am a little bit different than other people. (Connectedness and Isolation)
- KEN (Comfort & Annoyance) I mean I have the device and the hospital is only a short way from here, so I should make it, that's the whole point of the device. I was angry and disappointed... It pissed me off! (Trust/ Absence of Trust and Understanding)
- GAIL (Freedom and Restriction) I don't have to worry about that, there's people all around me and the woman who teaches the swimming, the instructor, she knows I've got an AICD. So she kind of keeps tabs on me. And that kind of perturbed me. (Connectedness and Isolation, not viewed as support, but rather a source of anger)

Specialized Actions Related to Having the Device

Another element of the general structure of living with an AICD includes special actions created by the presence of the device. These

behaviors include (1) actions to make the physical presence of the device more comfortable to the recipient's daily being; (2) actions specifically to prevent the device from delivering a shock; (3) actions employed to bring resolution to conflicts surrounding the driving issue. The latter two actions could be condensed into a category of actions related to self-regulation. These actions emerge from the notion of trust/ absence of trust. The recipient trusts that his or her actions will influence the chances of a shock. Persons who drive after the recommendation is made not to drive, trust their driving skills and drive anyway. Those who do not drive, trust the person recommending the restriction.

There are numerous actions listed by the recipients that make the device more comfortable on a day to day existence. Many are conveyed in the themes already presented. Some of the actions include positioning for comfort while working or sleeping; other actions include the wearing of non-restrictive clothing to accommodate the device's physical presence, as well as avoidance of objects that may bump the device. These actions seem to emerge from the recipient's experiences and personal understanding of the device, including understanding what actions make the presence of the device more comfortable.

Various actions utilized to prevent the device from delivering a shock are also numerous. Some actions include stress reduction, diet changes,

monitoring types and amount of physical movement, and taking deep breaths at the recognition of preshock symptoms.

Actions employed to bring resolution to the conflicts brought about by the driving restriction are also numerous and vary. They include seeking assistance from others for transportation, dealing with guilt for continued driving, explaining and justifying continued driving to self and to others, and driving more carefully than before the AICD implant.

Symbolization of the Device and Its Action

Although all language is symbolic, there was a strong presence of a higher level of abstraction among the subjects in their references to the device and the actions of the device. The representations are a mixture of analogy and metaphor, but they convey a personalization of the device into their being that surpasses the device's material being. The symbols reveal attributes that demonstrate the device has become very particular and intimate. It seems that these descriptions emerge from the recipient's personal understanding of the device. They reveal a great deal about the process of assimilation. In the general structure it is not important who said what; what is important is that it was said. Symbols that have been used by the subjects in this manner and are presented in Table 2.

Table 2. Symbolizations

Metaphors, Allegories and Symbolic Descriptors Related to the AICD		
The box	Doctor with me	Dodged 3 bullets
Guardian Angel	Lifesaver	Ventrix
Insurance Policy	Safeguard	The silly thing
Security Blanket	Protector	Not alone with it
Filling in my tooth	Works like a good laxative	A sack

Model of the General Structure

Giorgi (1985) indicates that what he has presented with his method is really "only the tip of the iceberg" (p. 21). He indicates that "more remains to be developed than what has been achieved" (p. 21). In response to this, it seems that his method of analysis could be taken a step further. While remaining loyal to his method, a conceptual model of the experience of living with an AICD, might provide the mechanism by which the structure of the general description can be portrayed. The descriptions of the dimensions set the groundwork for such a model, as relationships among the dimensions are suggested. A conceptual model of living with an AICD is shown in Figure 4.1.

The model is grounded in time, as time is the ground of all experience.

The model exists in the context of the entire cardiac experience, as persons with AICDs cannot separate the AICD from its underlying purpose, and their cardiac events. The model is conveyed as the story of assimilation, as it is a narrative of the experience of living with an AICD. The story takes on different forms, but elements of the story are revealed in all of the situated structures that have been presented. To identify quotes that support the model would be redundant, and would defeat the purpose of the situated structures. Dimensions of the model have been discussed and supported, and this researcher invites the reader to go back to the situated structures if clarification is needed, as the model clearly emerges from the data.

The story of assimilation is a dynamic story in process that begins when the individual decides to have the AICD implanted. This decision is depicted in the dimension of choice/ no choice. Choice/ no choice is the catalyst for the beginning of the story. The story of assimilation is mediated by specific experience with the device primarily being the initial shock.

The core of the story is centered on three dimensions that in constant flux and operation. The dimension of trust/ absence of trust is a dimension that exists to some degree in all AICD recipients. This dimension involves trust/ absence of trust toward the device, health care professionals, and the

self. Emerging from this dimension are actions related to self-regulation including actions performed by the recipient in a trusting effort to prevent the device from discharging, and actions employed to negotiate the activity of driving. These actions include driving in spite of recommendations not to drive in which the individual trusts his or her skills, and the device to keep anything from happening. They also include justification and explaining to others reasons driving should continue. Conversely, persons who do not drive chose not to because they trust the wisdom of the recommendation, do not trust the device, or do not trust their ability to drive. As a result, the individual relies on others for transportation, and has confidence in the understanding of others to provide transportation.

Understanding is a core dimension that consists of personal understanding and the understanding of others. There is an overlap, in the sense that understanding is mutual, and the recipient perceives that others understand aspects of the experience the same way as the recipient. There are emotions that emerge from the relationship of trust/ absence of trust and understanding that can be depicted as syzygies. As levels of trust fluctuate, and understanding develops there are syzygies that center around trust of others, health care professionals, "the Lord," the device, and the self. Lack of trust is conveyed in insecurity, and fear. Different levels of trust manifest

different levels of confidence, security, as do different levels of understanding.

From personal understanding actions related to the physical presence of the device emerge. Recipients come to understand that bumping the device is painful. They come to understand that loose clothing is more comfortable than restrictive clothing. They come to understand that changing position makes the presence of the device more comfortable when they work, sleep, or perform other daily activities.

Symbolizations of the device also emerge from personal understanding of the device. As shown in Table 2, the words that the recipients use to identify their device or its actions convey more than a mechanical representation of the device. A intimate alliance with the device is conveyed in the metaphors used. These metaphors convey a personal quality of the recipient in his or her understanding of the device and its purpose.

Support is also a core dimension of the story. Support comes in a variety of forms and is not the same for all individuals. Identified support was conveyed through support groups, "the Lord", family members, friends, pastors, and health care professionals. Regardless of the form, one thing all support persons or systems have in common is that recipient perceives that the support persons or systems **understand** the recipient's experience. Persons who were not of support were those who did not understand. From the union

of varying levels of understanding from others and varying levels of support emerged syzygies of connectedness and isolation. People with limited understanding were less able to support, and more prone to treating the recipient's as different, or as "oddballs." Persons who understood the recipient's experience were viewed as supportive and a sense of being connected was conveyed, regardless if the other person had an AICD or not.

A limitation of this model as depicted in Figure 4.1, is that it can only appear on paper as stagnate. It is imperative to conceptualize the story as a very dynamic, unfolding, changing process. It is important to view the core dimensions of the model as expanding and shrinking, and rotating throughout, but within the story. This is the reason that there are return arrows from the syzygies to the other dimensions. The syzygies not only emerge from these dimensions, but impact the dimensions in the every animated story of assimilation.

Summary

The generalized structure of living with an AICD has been presented. The structure is in the context of a whole cardiac experience; it cannot be separated from antecedent events. There is a trajectory, or story of assimilation of the device into one's being that transpires over time. The story

is unique to each individual and is mediated by key experiences and understanding. Understanding involves both self-understanding and the understanding of others. Concerted effort to keep the device from one's immediate awareness is a part of the trajectory for some. The decision to have the device initiates the story and in many cases is an affirmation of life and values that accompany life. Even when the choice is made by someone other than the recipient, it is an affirmation of life. Gratitude is evident both general gratitude and gratitude for the device; it is the device that provides the choice. Support is an essential aspect in the experience of living with an AICD. Sources of support vary individually and can be identified only by the recipient, in spite of the intent of others to provide support. Trust is an integral part of the structure, and the recipient of the trust varies from person to person. Trust in the device, health care professionals knowledgeable about the device, and in the Lord were identified in the subjects. The experience of living with an AICD includes an assortment of emotional syzygies that vary from person to person and fluctuate within the person. Living with the device influences behaviors that are directed toward making the presence of the device more comfortable, preventing the device from shocking, and resolving conflicts associated with recommendations that restrict personal freedom, such

as driving. Symbolic representation of the device and its action reveals meanings and personalization of the device by the individual.

The Shock Experience

All subjects in this study had experienced a shock from the defibrillator. The meaning of the shock experience is manifest in the trajectory of assimilation. In some cases the shock was viewed as restoring order. In others it was the result of violating the regulations in activities perceived as imposed by the device. Yet in others, there was no clear meaning to the shock, other than an understanding of what was happening to the heart.

Because the shock sensation is unique and warranted description by the subjects, it is logical that a description of the experiences from each participant might be useful in describing the sensation to others. This could be useful in a variety of ways, and since it was important for the subjects to describe, would most likely be information prospective recipients would appreciate. This deviates from Giorgi's ideas, but the actual experience of the shock is so personal that a general structure of the experience would only dilute the richness of the descriptions. Table 4 identifies each participant and their description of the shock sensation in the participants own words.

Table 3. The Description of the Shock Sensation from Each Participant

Abe	Well, its kind of like, I guess you'd say, a young mule kicking you in the chest (Laughs). But ah, it's really not all that bad. I mean it's something that hurt, but taking everything into consideration, it feels pretty good too, otherwise, because you know it's doing its job.
Bob	It really didn't hurt. It was more a scare than a hurt. Felt like you stuck two fingers in a socket at the same time, the shocking part. And it'll shock you! If you get shocked, it's just an instantaneous thing, I mean it's not a lasting effect. You kind of feel a tingle all over.
Carl	I was at (fast food restaurant) getting ready to eat. I had just picked up the order and carried it over to the table and sat it down on the table. And just as I sat sat down, I said, "Ow!" It was just a shock. I had first thought the table had shocked me. It shocks hard enough to let you know it's there, but it wasn't that bad.
Don	Anyway, we were having sex and I felt this "WHACK!" Sudden jerk like that. Then I realized, "Hey, I know how this thing works." It only lasts a brief second then nothing else. It felt like a jerk forward, just like that. I had to jerk forward. There was not a pain, just a "poof," just like that. I thought someone had broken into our house and hit me in the back.
Eve	It's like getting kicked by a mule, but there's no point of impact for it to hurt. It will knock a sound out of you. You'll go "YIP!" You don't yell because you don't know it's coming. It just knocks the sound out of you. As soon as it's over, there's no lasting effects; no pain; no nothing. Just like somebody's hit you real hard, but there's not a place where it actually hurts where they've hit you. It just pops you.
Fred	Just like getting shocked. If you grabbed a couple of open wires, you know, and it raised me up out of the chair. I was sitting in the chair, oh I'd say a couple of inches, something like that. But it was over so quick that I never lost control of anything.
Gail	I thought I was going to faint. I just got, everything started to turn black, and I started to tell my husband that I was going to faint, and it shocked me. Now I mean I hit my chest so hard with both fists it really was a tremendous shock. If I hadn't been sitting down it would have knocked me over, I know, but it didn't. It scared everybody there half to death and I said, "I'm all right. I'm all right."

Table 3. (Cont.)

Helen	I just went through the dining room and leaned on back of the couch watching television and all at once I thought, "I'm having a heart attack!" And then I realized what it was. But it had like needles, thousands of needles in my arm and like somebody had hit me in the chest like that, you know, with their fist in my chest.
Ian	It just kind of lifts you up, it sounds like a bomb went off in your head. Of course you can't hear it on the outside, but to you, it felt like a bomb went off. It really gives you a jolt and almost pops your neck, you know. But then immediately as soon as the shock is over, I've always felt great.
Jill	A like thing would be when you have static electricity and you touch something and it shocks you, now that's very light. Multiply that several times, and it hurts. Because it makes you jolt. It actually picked my legs up when it went off.
Ken (70 Shock Malfunction)	They were just like picking up two loose electrical wires and getting a real jolt. I mean it shakes your whole body, down to your feet! I would yell each time it went off, not that it was that painful, because at first it wasn't, but more to relieve the pressure. I didn't have to I guess. When I was a boy on a farm, we used to have electrical type fences. Sometimes we would grab them, a group of us to see who could hold on the longest. I know it sounds silly now, but it was something to do. The shock is about like that only you can eventually let go of the fence, but I couldn't this!
Lee	Well, the first time it's not, I don't know, probably no more than getting a hold of a spark plug or something. Second time is just a little stronger and that third and fourth is probably like standing in water and getting 110 volts. It's a pretty good shock. But the first one will make you holler if you're not expecting it. But I mean, I don't know, I'd say the first one's probably no more painful than a wasp sting or something like that. But, you know, if you're not expecting anything, why, it's enough to make you jump, you know, you don't know what's hit you.

CHAPTER 5

Summary, Implications and Recommendations

Once there was a village where all the inhabitants were blind. When a man passed one day riding an elephant, a group of the village men cried out asking the rider to let them touch the great beast, for they had heard about elephants, they had but never been close to one.

About six of them were allowed to approach the animal, each being led to touch a different part of the body. After a time the rider left, and the blind men hurried back to their people to share the experience. "With what can you compare an elephant?" the people in the crowd asked their six friends.

"I know all about elephants," cried the man who touched the elephant's side. "He's long and narrow, built like a thick wall."

"Nonsense," shouted the man who had touched the elephant's tusk. "He is rather short and round, and smooth, but very sharp. I would compare an elephant to a spear."

A third, who touched the ear, joined in. "It is nothing like a wall or spear. An elephant is like a gigantic leaf made of thick wool carpet. It moves when you touch it."

"I disagree," said the man who handled the trunk, "An elephant is much like a large snake."

The fifth man shouted his disapproval. He had touched a leg of the great beast. "It is plain to me that none of you have described the animal accurately. It is round and reaches toward the heavens like a tree."

The sixth man who had been placed on the elephant's back, cried out, "Can none of you accurately describe an elephant? He is like a gigantic moving mountain."

To this day the argument has not been resolved, and the people of that village have no idea what an elephant looks like. (White, 1982, p.78)

Overview of the Study

Existential phenomenology was used to formulate a description of the lived experience of living with an AICD. Data were collected from interviews with 12 persons who have an AICD. The interviews were audiotaped and

transcribed verbatim. The transcripts were analyzed using the method of analysis suggested by Giorgi (1975, 1986). For each participant a situated structure was rendered. Themes were then incorporated into elements that are trans-situational to make the general structure. This structure combines experiences of the participants and constitutes the experience of living with an AICD.

Summary of Findings

The cardiac experience provides the context for the implantation of the AICD and in essence a part of the whole notion of health. The AICD cannot be separated from the heart or the history of the cardiac events that lead up to the implantation. It is a therapeutic modality for an underlying cardiac problem and is perceived as such.

There is a process of assimilating the device into one's being. The process is grounded in time, and varies from individual to individual. The dynamic process is mediated by experiences and by understanding. Understanding includes the understanding of the recipient and the understanding of others. Both impact the experiences of the recipient. The uniqueness of the individual is important in the trajectory as the progression is not the same for everyone. Experiences and the meaning of those experiences

differ. Some experiences suggested as mediators include the first shock, knowledge of the device after conversations with the physician, and talking to others about their experiences. The importance of others emerges in the trajectory and serves to enhance self-esteem associated with the device.

Recipients indicate an appreciation for life and an awareness of the proximity of death in situations where the AICD is introduced. Choosing the AICD dictates a confirmation of the value of life for the individuals who chose to have the AICD. Some participants perceived there was "**no choice.**"

Support for persons with an AICD varies according to the individual's needs and interpretation of the support. Support is a common thread and need among persons with AICDs. Support comes from family, friends, pastors, and formal support groups. Family members, especially spouses, provided the most support. The types of support and the need for amount of support fluctuates from time to time and from person to person. In Lee's case, his son's non-special treatment was perceived as support.

Formalized support groups are beneficial for some of the recipients. They provide an arena of "sameness" for some, and for one individual the support group provides a group of people for comparison. The support group does serve as a reminder of death and illness for some.

Trust is an essential element of the general structure of the lived experience of persons with AICDs. Trust in the device, trust in persons knowledgeable about the device, or trust in a spiritual being, are evident among the participants. Total trust in the health care system is not evident due to several circumstances that were conveyed by the participants. Trust in the device is evident in the choice to have the AICD, as in essence the recipients are trusting their lives to their AICDs. Trust in people knowledgeable about the device is obvious in the choice to have the device.

Syzygies of feelings are evident among the recipients. Syzygies are not conflicts; they are emotions that are seemingly contradictory yet exist at the same time, and are part of the whole experience of living with an AICD. There is not a resolution to a syzygy. The importance of the syzygy lies in its identification, and in the meaning and impact of the syzygy on the individual.

The syzygies assumed different forms, but they were obvious in all recipients to some degree. As the participants were at different points in their stories of assimilation, the syzygies varied. Inherent in the syzygy is movement and change, which are part of the story of assimilation. It is important to note that an interview is locked into a certain time. Even though experiences of the past are related in the interview, experiences change the person such that the opportunity to discuss living with the AICD may effect a

change in the person being interviewed. Some realizations occurred in the interview that indicate the person at the end of the interview was more aware and not exactly the same as at the beginning of the interview. The sides of the syzygies fluctuate in time and patterns. What is revealed of the syzygy is what is occurring at the time of the interview.

Throughout this study, the experience of living with an AICD is multidimensional is conveyed. This has ramifications for some of the unidimensional studies discussed earlier.

There are certain aspects of living with an AICD that are more physically troublesome than others. It seems that for the women attire is more of an issue; for men, physical activities that are hampered or altered by the presence of the device require behavioral changes. Each participant develops distinct behaviors to accommodate the physical substance of the device.

Behaviors aimed at controlling the incidence of being shocked are also utilized by persons with AICDs who perceive a linear cause and effect in their behavior and the shock. Many of the behaviors described can be categorized as behaviors to promote good health. Some specific behaviors during preshock symptoms may be instrumental in averting a shock. Deep breathing may indeed increase oxygenation to eliminate the incidence of ventricular

tachycardia. The health promotion behaviors are behaviors directed at exercise, stress management and dietary changes.

Driving remains an issue for AICD recipients. The current recommendation is not to drive initially. There remains much debate among cardiologists and device companies about the recommendation. In the meantime, the recommendation generates feelings of dependence on others, feelings of guilt for some who continue to drive, and feelings of justification accompanied by logical arguments for not following the recommendation. Driving was a recurrent issue and one that remains controversial for all involved. There is some speculation that legislation and insurance companies may remove the controversy from the health care arena. This may impact AICD recipients in a variety of ways, especially those who not only wind up violating physician recommendations, but also legal and financial responsibility for driving.

All language is symbolic. Words represent thoughts and objects. Some words convey more than the physical presence of an object. This was found to be true in many subjects' references to the device. The metaphors and allegories demonstrate a personalization of the device and reveal attributes of the device that have meaning to the individual. Symbolization of the device

and the action of the device is found among many of the participants in the disclosure of their experience of living with an AICD.

Implications for Nursing

It is important that the AICD be considered within the context of the entire cardiac history and experience of the individual. Focusing on the AICD is important, but the context is well established by the recipients. Nurses and health care professionals need to look at the whole picture as presented by the recipient. To focus only on the device obliterates the context of the AICD, and alters its meaning for the recipient. An understanding of the cardiac history and the meaning of the events as conveyed by the recipient would lead to a deeper understanding of living with the device and the meaning the device has for the recipient.

The individualistic nature of the trajectory is imperative for nurses to realize. Not everyone is prepared to receive and incorporate information at the same rate or at the same time in the process. Teaching should be continually evaluated and reinforced in order to be effective. This is evident in the case with Ian who did not understand the purpose and function of the device for over three years after having the device implanted. Nurses also need to identify key experiences in the recipient's trajectory and help them

comprehend and interpret the meaning of those experiences at the individual's place in the story or trajectory. Awareness of the unique nature of the individual should be the guide to any and all interventions. Nurses need to constantly expand their knowledge base so that understanding is conveyed.

Support systems for persons with AICDs need to be identified and encouraged. Support was essential to all of the participants and it is significant that support comes from various persons and groups, and takes different forms. Groups constructed to give support by health care professionals may not be meeting the need. This is not a reflection of the support group, but rather a indication of the recipients' individual differences and requirements. Support groups should be facilitated to provide meaningful information and time for interchange among the recipients and their families.

Nurses are in a unique position to recognize groups and individuals that recipients identify as support systems. Nurses can enhance support by identifying the source, and providing encouragement, education and awareness. Nurses can bend the visitation rules in hospitals when the support system of the AICD recipient is available. Nurses can encourage the support person's active participation in acute treatment and care when the situation arises and equip him or her with information about the device.

Trust is an element identified in all participants. Trust is directed differently, but an underlying trust in the device and persons knowledgeable about the device is apparent. Nurses need to become more knowledgeable about the device, so that trust can be intensified. Trust between a patient and nurse is an essential element to the nursing profession. Circumstances that have caused harm to the participants have been the result of lack of knowledge about the device. Harm to patients is incompatible with trust. To be proponents of persons with AICDs, nurses must become more knowledgeable about the device and the experience of living with the device. Knowledge of the experience of living with the device can only be the result of personal empathic interactions with AICD recipients and studies such as this.

The presence of syzygies has numerous implications for nursing. For nursing research, it is a clear indication of the multidimensionality of the lived experience. Tools used to study anxiety or depression in persons with AICD are limited in scope. As a result they are limited in their usefulness to clinical application. By identifying both components of the syzygy, and measuring both components of the syzygy, a picture based in the reality of experience can be explored.

Nursing diagnoses can be developed that complement the part of the syzygy that is often identified as a need. If value judgements are assigned to

anxiety, fear, depression or insecurity, complementary judgements can be ascribed to security, confidence, or comfort. The researcher of this study warns against appointing values to syzygies, and this is not his intent. It is his opinion that the components of syzygies are not necessarily good or bad, but rather they **just are**. By virtue of their existence among persons with AICDs they warrant identification and examination. Studies that have measured fear among these subjects are incomplete without measuring the another attribute that is seemingly antithetical.

Nurses can help recipients identify syzygies in their experiences and occurrences in which certain aspects predominate. Then the individual can determine for his or herself the aspect that is most useful to explore and cultivate.

Specialized behaviors that help the recipient deal with the physical presence of the device should be noted. They might serve as alternatives for newer recipients and potential candidates. The use of maternity hose as an alternative to larger hose, or tight hose, is a creative option used by Gail that might not come to another's immediate awareness. As necessity results in design, it is logically that persons who have the device create options. These options warrant sharing. This study only illuminates the notion that options

are created and exist; it is not the purpose of the study to reveal or list options.

Behaviors related to preventing the device from firing are health promotion behaviors for the most part. Nurses need to encourage these behaviors in all persons. Individual behaviors that the recipient finds useful should be examined in detail to assure safety and, once sanctioned, should be encouraged. There is always the possibility that recipients may engage in preshock behaviors that are perceived as beneficial that might actually be harmful. It is important to note that these behaviors exist and are part of the individual's management of the device. Acknowledgement of this has not been indicated elsewhere in the literature.

Acknowledgement of the driving issue and matters surrounding the driving issue are identified in the literature. There are many implications for nurses. Some states have legal statutes that guide nurse and physician recommendations. Some states do not have legislation regarding driving for the AICD recipient. It is important for nurses to know how their states stand on the issue. It is vital to know the health care team's views on driving. What is equally important for nurses is the recognition that driving in and of itself is not the only issue. Issues of guilt, rationalization and independence

filter into the driving conflict. The nurse must identify underlying issues and help the recipient resolve and to identify alternatives.

Symbolization of the device and its actions is important as it reveals aspects of the device that have been personalized by the recipient. There are meanings attached to these symbolizations that should be explored in clinical settings. These very emblems may reveal something about the recipient's trajectory, or their ability to cope with the device. The phrases and terms in Table 2 primarily reveal a sense of security about the device. This may not always be the case, and it is important for nurses to regard the language of the recipient as it may be more revealing than intended. Nurses can then augment, or explore those meanings with the individual to enhance understanding for both the recipient and the nurse.

The findings of this study have many of the same implications that were suggested by Cooper, Luceri, Thurer and Myerburg (1986). As they determined that the AICD implantation is associated with multiple social, physical, and psychological changes, a multidisciplinary approach to assist recipient's adjust is warranted. Fear and anxiety existed among the recipients of this study, but did not seem as widespread as discerned by Cooper, Luceri, Thurer and Myerburg (1986). This may be due to the advancement of the device, it's more prolific use than in 1986, and the fact that it is not as novel

as it was in 1986. Although novelty should not necessarily be a factor, this is concluded as a result of the literature search on persons with pacemakers. The device has absorbed into our culture such that persons with pacemaker have not been the foci of recent studies. With the rapid technologic developments in cardiology with Left Ventricular Assist Devices, perhaps in several years the AICD will become commonplace.

Relationship of Findings to Parse's Theory of Human Becoming

The study was not based on a theoretical structure or framework, but rather on philosophical underpinnings of existential phenomenology. The value of the findings is enhanced when presented in a nursing perspective. Parse's theory of human becoming (1981, 1992, 1995) is a human science theory that provides a harmonious structure by which the findings of the study can be interpreted. The theory is compatible to the philosophical underpinnings of the study, and is consistent with Giorgi's (1975, 1986) notions and method of seeking to understand phenomena as they are lived.

Parse's (1981, 1992, 1995) theory has its foundation in the belief that humans actively participate with the world in cocreation of health. Health as conceptualized by Parse is an individualistic experience related to perceived quality of life that can only be defined by the person. Health is a continual

process of human unfolding. As people live, they live health and in so doing, they reveal values and ideas which are their attachments to the world. The substance of Parse's theory is set in meanings and patterns.

There are three major principles in Parse's theory of human becoming. The principles are presented at the theoretical discourse level. Aspects of the generalized structure can be applied to the three principles and will be discussed in relation to the principles. As presented by Parse (1981) these principles include:

1. Structuring meaning multidimensionally is cocreating reality through the languaging of values and imaging....
2. Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing, enabling-limiting while connecting-separating...
3. Cotranscending with possibilities is powering unique ways of originating in the process of transforming. (p. 69)

The first principle relates to the study in that it assumes the experience of living with an AICD is endowed with meaning and that structuring that meaning is linked to valuing and imaging. The element of the lived experience of persons with an AICD that supports the notion of valuing is the affirmation of life. The value of life and the value of the lives of others is

inherent in the lives of persons with AICDs. The factors that went into the decision to have the AICD were unique and personal for each person. The narration of that choice is expression of the person's uniqueness in the world. An example of this most obvious in Eve's portion of the analysis.

The first principle encompasses the notion that "moving and speaking are symbolic ways of languaging imaged values in the cocreating of reality" (Parse, 1992, p. 37). Evidence to support this principle is in Table 2. The metaphors and analogies used to describe the device and its action reveal a meaning that the device has in the recipient's life.

The second principle of cocreating rhythmical patterns of relating as living in paradox is evidenced by the identification of the syzygies of feelings. The identification of the syzygy is harmonious with Parse's (1992) notion of paradox as "these rhythmical patterns are not opposites; they are two sides of the same rhythm that coexist all at once" (p. 38). Revealing-concealing embodies the idea that people reveal one aspect of themselves while they conceal another aspect. This is typified in Lee's dread of having the battery changed in two years. In his dread there is concealed hope, hope that he will be around for two more years to have the battery changed.

Enabling-limiting implies that as people move in one direction they are presented with opportunities that limit movement in other directions. As Lee

chooses not to think about the device, he is limiting his understanding of the device. In Lee's case, because he did not know what to do once he received his initial shock, he allowed the intervention of the ambulance attendants, which caused him to experience multiple shocks. By choosing to ignore the existence of the device, he limits his agency to deal with the device when it cannot be ignored.

Connecting-separating in Parse's second principle is also evident in Lee. As he chooses to move toward situations where he is with people who do not have the device and do not remind him of the device, he separates himself from people who do have the device. This clearly holds limitations and opportunities in connecting with some and separating from others,

"Cotranscending with possibilities is powering unique ways of originating the process of transforming" (Parse, 1992, p. 38), reflects the uniqueness of the individual in the universe as they continually unfold. Powering and originating propel transforming, which is evident in the element revealed as the trajectory of assimilation. Transforming according to Parse (1992) "is the shifting of views of the familiar as different light is shed on what is known" (p. 39). This notion is manifest in the explanation of the story as mediated by understanding and experience. Understanding and experience transform the individual, such that the individual is changed by the experience,

the interpretation of that experience, and understanding that emerges from the experience.

Although Parse's ideas were not a part of this process, the harmony of the theory to the research findings support the rigor of the research. At the same time the findings support the strength of the theory. The attachment of the theory to research is coupled with a therapeutic element to this study as the researcher listened to the participants' stories. This blend demonstrates that the separation among nursing practice, research, and theory is artificial. In reality they are parts of the whole of nursing.

Limitations of the Study and Recommendations for Further Research

This study was limited in that it consisted of only one interview per participant. After reflection and analysis, the researcher speculated that multiple interviews might have revealed more about the story and about the syzygies. A longitudinal study would enhance the description of the trajectory.

Further research should include AICD recipients with more diverse ethnic and racial backgrounds. Although attempts were made to interview recipients from a wide geographical area, all recipients were still from the same part of the United States. As all of these factors affect experience and

the interpretations of experiences, a more diverse group of subjects might yield richer data, which would add depth to the general description.

Each of the elements have tremendous potential for further research ranging from a description of behaviors associated with those discussed as specialized behaviors, to further exploration of the syzygies of persons living with an AICD. Each element presents a study of its own.

Some may consider the use of phenomenological method, which provides understanding without indicators of causality, to be a limitation. While the method does not imply or present causality or predictors of isolated concepts, it does provide understanding of the experience of living with an AICD.

Personal Reflections

Conducting this study had a great deal of personal meaning and provided a great deal of personal satisfaction. Most of that originates from the strong desire to understand the lived experience of living with an AICD. I have been sharing my understanding all along with others, as well as confirming my understanding as it continues to unfold.

My understanding of nursing has also been enhanced by this study, as I have proven to myself that the segregation of nursing practice, theory, and

research is artificial. The research question was born in clinical practice, explored in research, and supported by theory. The findings do not stop here, but have already been incorporated into clinical practice. Even during the interviews some of the participants came to new realizations and understandings, which is part of the process and another way that the three areas of nursing overlay.

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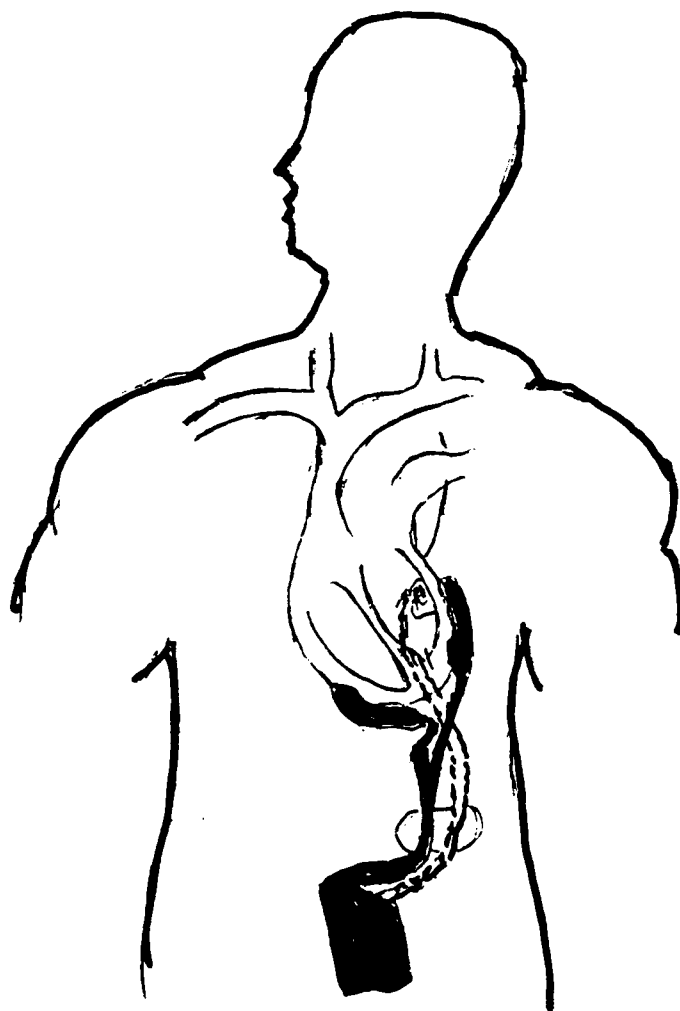
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Appendices

Figure A-1. The Automatic Implantable Cardioverter Defibrillator.



Appendix B. Consent Form.

Living with an Automatic Implantable Cardioverter Defibrillator (AICD)

Consent Form

You are invited to participate in a research project. The purpose of this study to explore the experience of living with an AICD. As the number of people who are eligible to have the device implanted continues to grow, it is important for the general public, and health care providers to know what it is like to live with an AICD. The best source for this information is from persons who live with the device on a day to day basis. This study seeks to ask adults who have had the device for at least six months about the experience of living with the device. The interview will be conducted by the investigator who has worked with people in health care for many years.

You will be asked to participate in an audiotaped interview that will last approximately one hour (maximum of two hours) in a place of your choice. You will be asked to share your experience of what it is like to live with an AICD. Subsequent questions will follow and will be based on your comments and responses. This interview will be audiotaped so that the investigator can use your exact words to compare with words of others who have an AICD. These interviews will be transcribed into written form to allow comparative analysis. Your name will not appear on the tape or the transcript and will be known only to the investigator and kept in a locked file with tapes and transcripts at the University of Tennessee, College of Nursing. You may be contacted by the investigator following the interview and during the analysis to clarify the interpretation of your experience. This follow-up interaction will also be recorded. Upon completion of this study, the transcripts and code book, linking your name to your tapes will be destroyed along with the all of your tapes themselves. No incentive is available to reimburse for your time and effort in participating, however, you may personally benefit by talking about your experience.

The nature and direction of the interview will be determined by you and the investigator and will unfold as the interview progresses. Some areas of exploration have the potential to produce some concerns, anxiety, or embarrassment. You are free not to answer any questions. You are free to choose not to participate or you can withdraw from this study at any time without penalty. Upon withdrawal from the study, your audiotape will be destroyed. You can withdraw from the study by contacting the investigator or co-investigator whose phone numbers appear below.

Any and all information you provide will kept in confidence. Your name will not be used in any reports although your words may be used to support the interpretation and analysis. At no time will your words be linked, or traceable to your name.


Stephen D. Krau, RN/MA, MSN
Investigator

SUBJECT'S STATEMENT:

This study has been explained to me and I voluntarily consent to participate in this study. I have had an opportunity to ask questions and understand that I may ask further questions at any time in the future by contacting the investigator named above. I can withdraw from the study at any time without penalty. I have received a copy of this consent form.

Signature _____

INVESTIGATOR: Stephen D. Krau, MSN, RN
Doctoral Student
College of Nursing
(615) 974-4151

CO-INVESTIGATOR: Inez Tuck, RN,
Associate Professor
College of Nursing
(615) 974-7626

Appendix C. Interview Schedule.

1. I am interested in learning about the experience of living with an AICD. Tell me about living with an AICD.
2. When are you most aware of your AICD?
3. How does your AICD affect your day to day activities?
4. What activities in your life have changed since the implantation of the AICD?
5. How is living with an AICD different and/or similar to what you thought it would be like before you had the implant?
6. How did you decide to have the device implanted?
7. How has the device affected your interactions with family members and friends?
8. How do people treat you?
9. Throughout the decision to have the AICD and now, what type of support has been most important and helpful to you?
10. What are you most concerned about now?
11. If someone who was a candidate for an AICD came to you and was having trouble deciding whether or not to have the device implanted, what would you tell them?
12. Is there anything about the device we have not talked about that you would like mention?

Appendix D. Group Confidentiality Statement.

Agreement to Maintain Confidentiality
Qualitative Research Group

I, _____ agree not to discuss or disclose any of the content of the transcripts for the dissertation titled **An Existential-Phenomenological Study of Living with an AICD (Automatic Implantable Cardioverter Defibrillator)** to anyone other than the members of the Qualitative Research Group in the College of Nursing, or the members of the Phenomenology Research Group in the College of Psychology. Any and all discussions concerning the transcripts will be done exclusively in the presence of the primary investigator and will be done only for the purpose of analyzing data, or validating decision trail of the analysis.

DATE: _____

SIGNATURE _____

VITA

Stephen D. Krau was born in Hiedelberg Germany. He attended public and Department of Defense Schools in five different states and Japan. He graduated from Willingham High School in Macon, Georgia in 1970. That year he entered LaGrange College, in LaGrange, Georgia, and graduated in 1973 with a Bachelor of Arts degree in social work. In December of 1974, he received a Master of Arts degree in Church and Community at Scarritt College for Christian Workers in Nashville, Tennessee. Upon returning from Zaire, Africa as a United Methodist missionary, he entered Incarnate Word College in San Antonio, Texas. He graduated with a Bachelor of Science in Nursing in 1980. While serving as a U.S. Navy Nurse Corps Officer, he obtained a Master of Science in Nursing in 1989, at St. Xavier College in Chicago, Illinois. He was accepted into the doctoral program in the College of Nursing in 1991 and was awarded a Doctorate of Philosophy degree with a major in Nursing in August 1995.