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RELATIONSHIP BETWEEN COPING STRATEGIES AND PERCEIVED QUALITY OF LIFE IN ICD RECIPIENTS

By

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A THESIS

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ABSTRACT

RELATIONSHIP BETWEEN COPING STRATEGIES AND PERCEIVED QUALITY OF LIFE IN ICD RECIPIENTS

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A descriptive, correlational design was used to examine the relationship between use of the 8 coping strategies as identified by Jalowiec (1987) and quality of life (QOL). In addition, relationships and differences among demographic variables and stressors, as well as answers to open ended questions were examined. Thirty-nine Implantable Cardioverter Defibrillator (ICD) recipients who were $\geq$ 1 year post implant completed the Jalowiec Coping Scale, a revised Quality of Life Index Scale, and an informational questionnaire. Betty Neuman's conceptual framework for nursing provided the theoretical framework for this study.

There were no statistically significant results found from the data of this study. However, it was discovered that ICD recipients rated an overall high QOL (mean=68, range 0-100). It was noted that the 3 most used coping strategies were optimistic, supportant, and self-reliant. Subjects responses to the open ended questions were similar to those that have been noted in the literature.

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CHAPTER 1

INTRODUCTION

Introduction

Sudden Cardiac Death (SCD), as a result of malignant ventricular dysrhythmias is one of the leading causes of death in the United States today, accounting for approximately 300,000 deaths each year (Myerburg, Kessler, & Castellanos, 1992). SCD is defined as an unexpected, witnessed death of an apparently well person resulting from cardiac dysfunction and occurring within 1 hour of the onset of new symptoms (Featherston, 1988). Although tremendous strides in antidysrhythmic drug therapy have improved both the outlook and survival of these patients, there remains a large percentage (20%) who cannot be helped by conventional drug therapies (Cardiac Pacemakers, Inc., 1992).

The development of the Implantable Cardioverter Defribrillator (ICD), a device that recognizes and treats life-threatening dysrhythmias, is rapidly becoming a common treatment option for survivors of SCD (Teplitz, Egenes, & Braski, 1990). Since the first clinical implant in 1980, over 30,000 devices have been implanted in patients with ventricular dysrhythmias refractory to antidysrhythmic agents (Willerson, & Cohn, 1995). Once implanted the device can reduce the one-year mortality rate after resusitation from a SCD from 40% to less than 2-3% (Powell, et al., 1993; Palatianos, et al., 1991).

Many of these patients have survived one or more episodes of SCD or experienced sustained, symptomatic ventricular tachycardias. These events generally challenge patients to confront their mortality for the very first time (Featherston, 1988). Other sequelea include, overwhelming fear of recurrent SCD, sleep disturbances, powerlessness, anxiety, and depression (Noel, et al., 1986; Pycha, Gulledge, Hutzler, Kadri, & Maloney, 1986; Owen & Harrison, 1985; Rossi, 1984; Davidson, VanRiper, Harper, & Wenk, 1994).

Following implant of the ICD, patients still have many lingering fears, such as: device malfunction (trust-worthiness), premature battery depletion, loss of control related to device dependence, thoughts of death, discomfort of shocks, fear of device firing, pain, public embarrassment from firing of device, loss of consciousness, an ability to return to a functional life-style, and need for frequent follow-up (Noel, et al., 1986; Tchou, et al., 1989; Brodsky, et al., 1988; Bainger & Fernsler, 1995). ICD recipients make many adaptations which include:

decreased physical activity, decreased sexual activity, dependency, changes in body image, preoccupation with their heart condition, and daily awareness of the ICD (Cooper, et al. 1986; Brodsky, et al. 1988; Pycha, et al. 1990).

Nurses work with recipients throughout the acute stages, as well as into the recovery phases following implant. A major focus for nursing is to assist the recipients to understand their ICD, as well as cope with the deleterious effects of the stressors. Different types of stressors are associated with the use of different types of coping strategies (Panzarine, 1985). The result of successful coping is the resolution of the stress or mastery over the stressors (Miller, 1983). An individual's coping capacity will determine his/her success at maintaining system stability. Thus, nursing interventions may be more effective if individualized to the coping strategies of the client.

Lazarus and Folkman (1984) describe coping as strategies used to deal with a threat. Coping consists of both cognitive and behavioral efforts aimed at mastering a stressful transaction. Coping efforts can be focused either toward dealing with the problem itself or managing the unpleasant emotions that are aroused because of the problem (Lazarus & Launier, 1978). How an individual copes is an important factor mediating the relationship between a stressor and the individual's eventual adaptation

(Pazarine, 1985).

Kuiper & Nyamathi (1991), and Lazarus & Launier (1978) report that the perceptions, stressors and the strength of the individual's coping strategies influence their quality of life. ICD recipients have been found to need a large repertoire of coping strategies to deal with the imposed stress of the device. Thus, nursing's goal should be to identify coping strategies used, build upon and strengthen these, bring increased energy into a client's system and move them toward an optimal state of wellness (Neuman, 1989; Nieves, Charter, Aspinall, 1991). This state of wellness should then reflect a desired level of self fulfillment and perceived quality of life (QOL).

Problem Statement

Many stressors and threats can be dealt with by people if given the awareness of and the skills to cope with them. Therefore, it is important to identify specific fears, problems, and information that would be helpful for patients to cope with receiving an ICD device. The outcome for a better QOL post-implant may be achieved when utilizing this information, along with strengthening a person's coping skills.

Purpose

By identifying coping strategies, as well as fears and anxieties, nurses should be able to appropriately center their education pre and post-implant. This education and emotional support will assist patients to better use their internal strengths to store energy, thus their coping abilities will improve. Those who can cope more effectively should then have the energy needed for a higher QOL.

The purpose of this investigation was to identify the type of coping strategies used by ICD recipients and examine their relationship with the perceived QOL of ICD recipients.

CHAPTER 2

Literature Review and Theoretical Framework

Literature Review

Research related to the stressors of having an ICD implant and its direct relationship to a recipient's quality of life (QOL) is scarce. Therefore, the literature review will focus on documented psychological responses, coping, and adaptation of ICD recipients to their device. In addition, general QOL issues and outcomes related to other groups of patients living with chronic illnesses will be presented.

Psychological Impact and Coping

Patients with life-threatening ventricular arrhythmias and those surviving an SCD event face many psychological sequelea that persist long after the dysrhythmic event (Featherston, 1988; Keren, Aarons, & Velte, 1991; Dunnington, Finkelmeier, 1988). Druss and Kornfeld (1967) initially addressed the emotional impact of SCD in 1967 through an investigation of 10 cardiac arrest survivors. The SCD survivors reported insomnia, violent dreams, anxiety, tenseness, restlessness, irritability, trouble concentrating, and activity restrictions beyond those medically necessary. Consistent with these findings, future studies (Runion, 1985; Featherston, 1988; Vlay, Olson, Fricchione & Friedman, 1989; Jenkins, Dunbar, & Hawthorne, 1994) revealed that fear, anger, depression, hostility, excessive fatigue, and tension also exist. For many patients this is the first experience of realistically confronting their mortality and the uncertainty of the future (Featherston, 1988; Vlay & Fricchione, 1985). Jenkins, Dunbar, & Hawthorne (1994), also found in their baseline data collection, of pre-ICD implantation patients, that feelings of dizziness (64%), tiredness (81%), anxiety about health (68%), interrupted sleep (61%), decreased sexual activity (64%), frustration (51%), palpitations (53%) existed prior to implant and may be attributed to the life-threatening arrhythmia as much as the device post-implant. This uncertainty for future SCD events leads some patients to develop a "time bomb" mentality which develops into hypervigilant behavior (Vlay & Fricchione, 1985). It has also been acknowledged that these potential, psychological stressors influence the autonomic nervous system predisposing the patient to ventricular dysrhythmias (Lown, 1987).

The psychological impact of the ICD device has been well noted in the literature. In preliminary observations, Pycha, Gulledge, Hutzler, Kadri, & Maloney (1986) noted that most patients eventually adapted well and accepted the ICD device, despite pre-implant anxiety. Their original study consisted of 2 women and 16 men with a mean age of 57. Psychiatric assessments which included the patient's perception of the device, subjective sense of well being, the presence or absence of emotional lability or major psychiatric problems, and family responses were conducted with 15 of the 18 patients. Subsequently, 6 of these patients completed 2 personality inventory scales. An adaptation questionnaire was also administered to 14 patients.

The observations were divided into pre-implant, early postoperative and later postopperative periods. The pre-implant period was one of crisis and patients universally had anxiety, fear, and need for information regarding the device. Once a decision had been made to have the device implanted the anxiety level decreased. Responses to the 2 personality inventory scales in the early postoperative period revealed moderate levels of self-doubt, depression, high levels of emotional upset and distress, and helplessness. Other findings were a sense of loss of security, control, and anxiety. All but 1 subject in the later postoperative period viewed their device as a life saver and symbol of psychological security.

Patients, however, were at different levels of acceptance. For example, one man developed a dependence on the device leaving him anxious and frightened when its batteries were due to be changed. Another man gave his device a name. Patients were also very anxious about the limited knowledge of the device in the health care community and were disappointed in having to cancel travel plans. Four patients had fears of their device firing which induced a state of hypervigilance causing sleep disturbances. Most mood alterations (i.e., presence or absence of depression) were related to a person's health status, degree of functioning, and the ability to work. The noted differences here reflect evidence that differing personality styles and attitudes hold varying outcomes for patients' QOL.

One limitation in this study was the small sample size. The number of different interviews and variation in regular follow-up from patient to patient due to distance restraints also may have influenced results. No statistics were listed in regard to percentages of responses. The study did identify that there were varying levels of acceptance and concluded that the use of adaptive denial skills could be attributed to those patients who adapted and adjusted well. The investigators discussed the need to include long-term patterns of adaptation in future studies.

In a subsequent study on patient and spouse adaptation to ICD implantation, Pycha et al. (1990), found that patients adapt to the ICD adequately but not without some reservations. In a retrospective study, 42 patients and 38 spouses were asked to complete a questionnaire to clarify psychosocial adaptation and device-specific concerns. Patient perceptions considered were as follows: a "life extender" (76.2%), a "source of anxiety" (4.8%), and "best friend" (4.8%). Patients viewed device discharges as being "not so bad" (21.4%), painful (16.7%), lightening-like (45.2%), and terrifying (14.3%). Patients' moods after device discharge were found to be either reassured or unchanged (52.4%), or nervous or tired (73.8%). Some patients (35.7%) felt self-conscious about the device, while 83.3% reported success with incorporating it into their body image. Noted life style alterations were reflective of health status with 75% stating they had been forced to retire due to heart problems. Also, 42.5% of the patients reported concerns that sexual activity would trigger the device to discharge. This particular study reported a low incidence of depression and anxiety and patients expressed some positive perceptions about the device. Also, 94% of the patients reported increased preoccupation with their heart condition since implant and nearly half of the patients expressed a desire for a support group. However, the retrospective design and the lack of structured interviews may limit generalization of findings from this study.

The prevalence of psychiatric disorders post ICD implantation was also noted in a study done by Morris, Badger, Chmielewski, Berger, and Goldberg (1991). A semi-structured psychiatric interview was conducted with a group of 20 ICD recipients between 3 and 21 months post-implantation. Ten patients (50%) showed varying signs of psychiatric disorder: 6 (30%) had transient adjustment disorder (mixed, anxious, or depressive in type), 3 (15%) had major depression, and 1 (5%) had a panic disorder. A statistical finding for psychiatric morbidity was associated with family problems, and a trend was noted with unplanned peri-operative shocks. It was also noted that when discharges occur early in the recovery process patient confidence in the device tended to decline.

Vlay, et al. (1989) studied anxiety and anger in 8 patients prior to implantation and 30 months thereafter. The group was examined using the Symptom Checklist-90, the State Trait Personality Inventory and a specifically designed questionnaire about the ICD. Results revealed a 26.6% decrease in the state anxiety overtime ($\underline{p} < 0.01$), while the state of anger remained unchanged. The trait scores were essentially the same before and after ICD implantation. Interestingly, it was found that the number of ICD discharges was reduced overtime revealing a trend ($\underline{p} = 0.094$). This may impact patients acceptance of the ICD, as well as their QOL. The greatest concerns given about the device involved recurrent arrhythmia and the implication for their prognosis. Seven of the 8 patients noted it worthwhile to have the device implanted.

However, in a study done by Keren, Aarons, and Velti (1991), it was noted that there were no significant differences in the responses to the questionnaire in the 2 groups of patients with and without discharges. A limitation of this study may lie in the fact that the accuracy of self-reports may be questionable due to people reporting not what they are like but how they would like to be viewed by others (Keren, et al., 1991).

In a descriptive study Kuiper and Nyamathi (1991) assessed stress perceptions and coping strategies through interviews and the Jalowiec Coping Scale (JCS). Average scores on the JCS for the 20 patients assessed, ranged from 0.68 to 1.7 (range 0 - 3). Optimism was the most frequently used emotion-focused strategy, whereas confrontive and supportant styles were the most frequently used problem-focused coping strategies. It was noted that subjects 50 years and older were less apt to use coping strategies of taking action, thinking positively, expressing emotion, and relying on themselves (Kuiper & Nyamathi, 1991). The similarity of the results retrieved from the two different collection methods supports and strengthens the conclusion that these subjects need a wide repertoire of coping strategies to deal with the stress imposed by the ICD (Kuiper & Nyamathi, 1991).

Nieves, et al. (1991) also noted in a study of the relationship between coping and perceived QOL in spinal cord injured patients, that those patients with the most effective coping mechanisms were the ones with the highest QOL. Testing and interviewing over a one year period was done using a convenience sample of 40 spinal cord injured patients from two different spinal cord injury wards. Coping effectiveness was measured using the Coping Effectiveness Questionnaire by McNett. Quality of life was measured using Padilla and Grant's (1985) Quality of Life Index. It was noted that coping effectiveness correlated significantly with perceived QOL (paraplegic subjects: $\underline{r}$ = .595; quadraplegic subjects: $\underline{r}$ = .535, total $\underline{r}$ = .606). This positive correlation suggests that nurses should incorporate patients' coping styles into their assessments, as well as find creative ways to teach coping skills to meet individualized patient needs effectively.

Quality of Life

Interest in quality of life (QOL) was first noted in the literature in the 1960's (Packa, 1989). A decade later, health-related QOL assessments became very popular (Zhan, 1992). Despite this popularity, the definition of QOL remains abstract and difficult to define, as well as the issue of how to assess QOL (Jalowiec, 1992). Zhan (1992) describes "QOL as the degree to which a person's life experiences are satisfying".

QOL is also viewed as a multidimensional construct that covers all aspects of life (Ferrans, 1990). With the tremendous strides in technology and treatment for cardiac disease, survival of patients is prolonged, but may not necessarily translate into an improved QOL. Thus, it is important to measure the effectiveness of these interventions and a patient's perceived QOL.

Researchers have identified five broad dimensions into which QOL domains can be placed: 1) physical and material well being, 2) relations with other people, 3) participation in social, community, and civic activities, 4) personal development and fulfillment, and 5) recreation (Campbell, Converse, & Rodgers, 1976; Flanagan, 1978). Flanagan (1978) also found that 95% of men and women of all age groups reported health and personal safety as important or very important to them.

Multiple physical, social and psychological alterations which have incurred from advanced technology also need to be examined. The impact of the ICD on life-style change for a group of 17 patients was studied by Cooper, Luceri, Thurer, and Myerburg (1986). They examined physical activity, social and psychological data using open-ended interview questions that focused on specific areas of interest. Some of these areas included: work history; physical, recreational, and sexual activity; descriptions of the shock; and other areas of concern necessitating life-style changes or adaptations. The patients were interviewed during a mean follow-up of 16 months after implant. It was noted that shocks occurred in 76% of the patients which resulted in significant fear (85%). They noted that the fear reflected a lack of warning prior to the shock rather than fear of the shock itself. Sixty-five percent had decreased their activity and 41% had decreased social interactions due to the limitation of heart disease or fear of shock. Decreased sexual activity or abstinence was reported by 41%. These results reveal quite clearly that having an ICD is associated with multiple physical, social and psychological alterations and adjustments.

However, there are several limitations to this study. One is the lack of a structured interview process and no discussion of coding the answers received. Another area of concern is that interviews were done over a time space as short as 2 months and as long as 21 months. One does not know if those who are so immediate post-implant are more vulnerable to the stress of an ICD or if there is a difference in someone's adaptation and coping of the device over time? The results were not analyzed comparing the responses to length of time post-implant and/or age. Studying these areas may be useful for assisting different groups of patients to adapt and cope with an ICD.

Reemployment after a major therapeutic intervention (i.e., ICD) is an important objective, behavioral QOL index measurement. Using a retrospective study, Kalbfleisch, et al. (1989) looked at 45 patients who were employed pre-implant. These patients were divided into 2 groups based on whether or not they returned to work after implantation. Greater than 60% employed before ICD implantation returned to work. The only significant difference between employed and unemployed patients were age (53 ± 11 vs 63 ± 9 years, $p < 0.001$) and education (13.4 ± 3 vs 11.5 ± 3 years, $p < 0.04$). Marital status was also found to be related to reemployment among ICD recipients. This suggests that ICD implant may provide social and emotional support and facilitate the resumption of age-appropriate work activities.

One limitation in the study may have been using the criterion of return to work which may have underestimated the number of patients who were highly functional after implant. There was no allowance made for patients who were physically capable of working yet chose not to work.

A more recent study on QOL by Bainger & Fernsler (1995), found that there were no significant differences in perceived overall QOL scores for ICD patients before or after implantation. Using a modified Quality of Life Index: Cardiac Version (QLI:CV) instrument, Bainger & Fernsler (1995) studied a convenience sample of 70 ICD recipients. Subjects were predominately male (82.9%) with a mean age of 62.3. The majority of patients (62.9%)

reported that they had one or more health problems. There were 49 subjects (70%) who had received shocks, with the mean length of time since the last shock being 9.85 months (range = 0 - 39). The mean level of discomfort was rated at 6.9 on a scale of 1-10. Some common complaints and psychosocial concerns were identified as: ICD size and location; limited range of motion; driving restrictions; and fear of being shocked. The QLI:CV scale revealed a significant reduction ($t = 2.19$, $p < .05$) in psychological/spiritual domain in post ICD implant ($M = 23.54$, $SD = 5.90$) than preimplantation ($M = 24.78$, $SD = 4.88$). Also, subjects who reported changes in work status post-implant scored significantly lower on health and functioning ($M = 20.87$, $SD = 6.20$; $t\ (68) = 2.49$, $p < .03$), socioeconomic ($M = 24.29$, $SD = 4.65$; $t\ (68) = 2.84$, $p < .01$), and psychological/spiritual ($M = 23.54$, $SD = 5.90$; $t\ (68) = 2.29$, $p < .03$) subscales.

Age was found to be an influence, in that subjects over 63 reported significantly higher overall QOL ($t\ (68) = 3.08$, $p < .005$) and higher QOL in each of the four domains compared with younger subjects. Sex, educational level, and employment status did not influence QOL measures for this sample. There were also no significant differences related to length of time since implant, experience of shocks, number of shocks received, discomfort associated with shocks, use of arrhythmia medications, support group involvement, use of beeper grams for follow-up ICD checks, driving and travel restrictions, financial concerns, family relationships, or changes in sexual activity.

There are a few limitations noted with this study, however. One is the nonrandom convenience sample of patients. Another is the retrospective nature of the study, with potential memory loss and under-reporting of symptoms. Subjects were also confused by parts of the modified QLI:CV scale which resulted in incomplete data and exclusion of subjects. The results of this study do suggest, however, that the ICD device does not prolong life with a sacrifice to QOL.

Supportive relationships have also been found to be direct contributors to a person's higher QOL and adjustment to illness (Burckhardt, 1985; Rheaune & Gooding, 1991). Burckhardt (1985) studied the impact of arthritis on quality of life for 94 adult men and women. Through the use of several scales it was discovered that subjects perceived support resulted in 10% of the explained variance in QOL.

Several multidimensional studies have been done to examine how physical functioning, family and social roles, and emotional adjustment affect QOL following heart transplant (Evans, et al., 1984; Buxton, et al., 1985; Lough, Lindsey Shinn, & Stotts, 1985). Lough, Lindsey, Shinn, & Stotts (1985) studied 75 questionnaires received from adult post heart transplant (> 6 months) recipients. The first part of the questionnaire asked them to rate their current QOL and satisfaction with their current state using a numerical scale from 1-6. The second part of the questionnaire examined life change since the heart transplant and the impact upon daily life. Results revealed 89% rating a good to excellent QOL and 82% rating life satisfaction as good to very satisfactory. Some factors found to contribute to a positive QOL post-transplant were: few health-related complications, physical endurance, sense of achievement, and future outlook. Overall the change in life style post transplant was perceived as being mostly positive. One limitation of the study was the range in time post transplant for the subjects involved. Subjects ranged from 7 months to 14 years post transplant. Lough (1985) noted that recipients who survived several years after the transplant had higher expectations for the future, even though they rated their current QOL equally as high as recent transplant recipients.

Packa (1989) studied 22 adult heart transplant recipients through the use of the McMaster Health Index Questionnaire (MHIQ) and the Cantril Self-Anchoring Scale. She also found that the most satisfactory assessment of QOL was found within the physical domain (0.94), followed by social (0.81) and emotional (0.71) domains (MHIQ range: 0-10). While all three scores were satisfactory, the social and emotional scores were the lowest. The Cantril Scale assessed QOL over three different points in time (1 month prior to transplant, at interview, and 5 years post transplant). Results revealed significant improvement in QOL after transplant, and this improvement was expected to continue until 5 years after transplant. Thus, it is very valuable for nurses to assess patients' coping abilities in all domains and assist them in understanding and anticipating changes required of them.

Theoretical Framework

Betty Neuman's conceptual framework of the Systems Model provided the framework for this study (see Appendix A). The structure of the model reflects its parts, subparts and their interrelationships for the whole of the client as a complete system (Neuman, 1989). The model is conceptualized as a holistic, open system and focuses on individuals and their reaction to stressors.

The client (individual, family, group, or community) is an open system interacting with the environment through interpersonal and extrapersonal factors. Each individual is a composite of 5 variables (physiological, psychological, sociocultural, developmental, and spiritual) which are subparts that form the whole of the client and influence the state of wellness or illness. Individuals are continuously exposed to various stressors in the environment and respond by adjusting to the environment or adjusting the environment. Through these efforts, the individual is able to maintain system harmony and balance, both internally and externally (Christensen & Kenney, 1990).

Each person is depicted as having three protective layers. The central core is composed of unique survival factors of the individual and consists of normal temperature range, organ strength, weakness, ego structure, and knowns or commonalities. The central core is first protected from stressors by the flexible line of defense. This layer is a dynamic, rapidly changing protective buffer that surrounds and protects the normal line of defense from stressors. Neuman (1989) feels that the greater the expansiveness of this line the greater the degree of protectiveness. This layer is highly vulnerable to internal factors such as loss of sleep, immune disorders, etc. When the cushioning effect of the flexible line of defense is no longer capable of protecting the individual against a stressor, the stressor breaks through to the next layer.

The second protective layer is the normal line of defense. This layer is viewed as an equilibrium state, a normal range of responses or levels of adaptation that have developed over time and are considered normal for a particular individual or client system (Fawcett, 1984). For example, coping patterns, life style, and the individual's usual ways of handling stress (Christensen & Kenney, 1990).

Lines of resistance are the third protective layer and are activated when the normal line of defense has been penetrated. These internal factors work to stabilize the person and foster a return to a state of equilibrium (Fawcett, 1984; Fitzpatirck & Whall, 1983).

Neuman (1989) views stressors as either noxious or beneficial. They are any situation, condition, force or potential source that is capable of causing instability of the system by penetration of the lines of defense. Stressors can be viewed as intra-, inter-, or extrapersonal in nature. Stressors vary in nature, timing, and degree and require energy to cope to return to a state of equilibrium. The reactions to these stressors are determined by natural and learned resistance found in the lines of defense. The amount of resistance is in turn determined by the interrelationship of the five variables that comprise the system. Other general factors that influence an individual's reaction to stressors are past and present conditions of the individual, available energy resources, the amount of energy required for adaptation, and the person's perceptions of the stressor (Neuman, 1989).

The environment includes both internal and external states that surround the client at any given point in time. The internal environment consists of forces within the individual (intrasystem); the external environment is composed of interpersonal (intersystem), and extrapersonl (extrasystem) stressors. Feedback between the client and the environment is circular in nature with a reciprocal relationship (Neuman, 1989). This relationship forms the basis of the two interacting elements 1) stress and reaction or response to it and 2) the client's subsequent health state (Scheel-Gavan, Hastings-Tolsma, & Troyan, 1988).

Health is viewed as a continuum of wellness to illness. It is dynamic in nature and is reflected in the harmony or balance of the individual's interaction and adjustment to the environment. Wellness is represented through the normal line of defense with more energy being stored than expended. A reduced state of wellness (illness) occurs when stressors penetrate the flexible lines of defense expending more energy than what is stored.

Nursing is seen as a "unique profession concerned with all the variables affecting clients in their environment" (Neuman, 1989). Nursing's goal is to move the client toward an optimum state of wellness by use of purposeful interventions. These interventions are aimed at the reduction or removing of disrupting stressors aiding in the conservation of energy in the client system. Interventions used by Neuman consist of 3 levels (1989). Primary prevention involves knowledge of all the variables that affect health. It is initiated before an encounter with a stressor to strengthen the flexible line of defense. Secondary prevention consists of interventions initiated after an encounter with a stressor. Here, interventions are offered to reduce the reaction by strengthening the normal line of defense and internal lines of resistance. Tertiary prevention is generally initiated after treatment and seeks to strengthen resistance to stressors by maintaining adaptation to prevent further negative reactions and maintain system stability.

Summary

In view of the above theory and review of the literature, it is evident that ICD recipients must adjust to many physical and psychological stimuli in order to survive. Even with the ICD therapy provided, it is a palpable reminder that the patient has a lethal illness and that these discharges coincide with life threatening events. While several studies have been conducted on patient responses to ICD implantation, none have directly measured the relationship of these responses to the patient's QOL. Some studies have shown that a patient's perception and strength in coping strategies influences his or her QOL. If this relationship does in fact exist, assessment of the individual by the nurse can promote successful coping strategies and reduce the stressfulness of ICD implantation.

As Neuman's theory states, if the patient does not adapt and cope to the stimuli and treatment they are faced with, they will continually expend energy (instead of store it) which will eventually lead to system death. Using her theory, having a higher QOL can be viewed as an adaptation or reconstitution of system stability toward optimal wellness. A positively perceived QOL enables patients to expend available energy and resources in other directions and strengthen their lines of defense. If we as nurses can identify successful strategies, fears, problems, and other helpful information, we may be able to influence patients who rate lower scores for QOL. By obtaining individual assessments of patients' current and past stressors and how they coped in the past we should be able to impart to them successful strategies that they can incorporate into their normal and flexible lines of defense. This will then move their system from an illness state to a more optimal wellness state. The energy stored in this state should result in the patient having higher quality in their life.

It has been well documented that many factors influence this process. Some of these include: physical functioning, side effects/results of the therapeutic intervention, lingering fears, and social and emotional support. ICD patients tend to need a wide repertoire of coping strategies to cope with the stress imposed by the ICD (Kuiper & Nyamathi, 1991). By obtaining information about support systems, fears, number of device firings, etc., and comparing this with scores on the Jaloweic Coping Scale (JCS) and the Quality of Life Index Scale (QLIS) nurses may be able to target appropriate interventions for ICD patients pre-implant to aide them in building and maintaining necessary coping strategies, and assist them towards a life of fulfillment and optimal wellbeing.

Research Questions

Using the Jalowiec Coping Scale (JCS) and the Quality of Life Index Scale (QOLIS) the following research question was explored in this study:

> What is the relationship between use of the eight coping strategies as identified by Jalowiec (1987) and QOL in ICD recipients?

In addition to the above, the relationships and differences among specific demographic variables and stressors, as well as answers to open ended questions, were examined:

1. Which of the 8 coping strategies are used most often by ICD recipients?
2. Which of the 8 coping strategies are identified as most effective by this client population?
3. What are the differences between types of coping strategies used and the demographic variables of

age, sex, marital status, support systems, ethnic background, and number of years of education?

4. What is the relationship between length of time since implant and QOL scores?
5. What is the difference between being in a support group and QOL?
6. What is the relationship between the number of surgeries for battery replacements and QOL?
7. What is the relationship between the number of shocks a person receives and QOL?
8. What is the difference between being able to return to work and/or school and QOL?
9. What is the difference in QOL in persons who have had restrictions placed on them?
10. What is the difference in QOL in persons who would recommend the device to others?
11. What are the responses of recipients to the open ended questions concerning:
    a) main problem since ICD implant,
    b) most helpful information to receive before implant,
    c) most helpful information to receive after implant,
    d) most common restrictions placed on persons' activities,
    e) would they recommend ICD implantation to a

family member or a close friend,

f) has their life changed since implant, and

g) greatest fear about your ICD device.

Definitions

ICD Recipient

An ICD Recipient: is an adult male or female who has undergone surgery for the implantation of an ICD device.

Stressors

The event(s) leading to the need for an ICD and the ICD implantation.

Coping Strategies

Coping is the individual's attempt to remove stress and restore physical and emotional equilibrium. Coping strategies are lines of defense utilized by recipients to deal with problems or the stress associated with health/wellness events, as measured by the Jalowiec Coping Scale (see Appendix B). Mean scores for use or effectiveness for each coping style and for overall scale are 0-3.

Quality of Life

Quality of life is viewed as an outcome which is affected by the strength of the individual's coping strategies, as measured by the Quality of Life Index Scale (see Appendix C).

CHAPTER 3

METHODOLOGY

Research Design

This study was conducted using a descriptive, correlational design to examine the relationships between coping strategies used by ICD recipients and their identified level of QOL. The subjects were asked to complete two Likert-type scales: one scale to measure type of coping strategies used and the second to measure the perceived QOL. Subjects were also asked to complete an informational questionnaire to determine relationships and differences between extraneous variables including: age, ethnic background, number of years having device, greatest fear, influence of support groups, and number of shocks received and QOL.

Setting and Sample

This study was conducted in physicians' offices as the patients came in for their follow-up ICD checks. The offices chosen were those in the surrounding lower Michigan areas whose physicians and hospital review boards agreed to participate.

The sample was one of convenience and included ICD recipients who were at least one year post-implant. Other criteria used for selection included: the ability to read, write, and speak English; 20 years of age and older; and voluntary participation as evidenced by their completing the questionnaires.

Instruments

Jalowiec Coping Scale (JCS)

The JCS was used to measure coping strategies used by ICD recipients. The original scale was developed in 1977 following an extensive review of the literature on coping and adaptation. The scale was revised in 1987 based on further research findings and ongoing literature reviews (A. Jaloweic, unpublished data, 1988). This scale examines coping behavior through a range of coping strategies, as well as coping effectiveness (see Appendix B). A specific stressor is listed on the front of the page allowing for situation-specific coping to be reviewed and compared. The scale is a 60 item, four point Likert-type scale. Using a 0-3 rating scale with 0 = never used, 1 = seldom used, 2 = sometimes used, and 3 = often used. Subjects were asked to rate how often they use each of the strategies to cope with the stressor listed on the front of the page. Using the same format, subjects were also asked to rate the effectiveness of each coping strategy identified. The revised version of the JCS uses a multidimensional approach in classifying coping strategies. Eight coping styles have emerged as being descriptive of the coping dimensions represented by the 60 items or questions. The eight coping strategies are labeled and include:

a) Confrontive (10 items) - confront the situation, face up to the problem, and constructive problem-solving. (Items: 4, 13, 16, 25, 27, 29, 33, 38, 43, and 45).

b) Evasive (13 items) - evasive and avoidant activities used in coping with a situation. (Items: 7, 10, 14, 18, 20, 21, 28, 35, 40, 48, 55, 56, and 58).

c) Optimistic (9 items) - positive thinking, positive outlook, and positive comparisons. (Items: 2, 5, 30, 32, 39, 47, 49, 50, and 54).

d) Fatalistic (4 items) - pessimism, hopelessness, feeling of little control over the situation. (Items: 9, 12, 23, and 60).

e) Emotive (5 items) - expressing and releasing emotions, and ventiliating feelings. (Items: 1, 8, 24, 46, and 51).

f) Palliative (7 items) - trying to reduce or control distress by making the person feel better. (Items: 3, 6, 26, 34, 36, 44, and 53).

g) Supportant (5 items) - using support systems: personal, professional, and spiritual. (Items: 11, 15, 17, 42, and 59).

h) Self-reliant (7 items) - depending on yourself rather than on others in dealing with the situation. (Items: 19, 22, 31, 37, 41, 52, and 57).

The overall scale for coping strategies is 0-180 and for coping effectiveness is 0-540.

Content validity for the scale has been empirically supported by a vast review of the literature (Jaloweic & Powers, 1981). Content validity is also supported by the large number of items used to tap the conceptual domain of coping and the inclusion of diverse types of coping behavior (A. Jaloweic, unpublished data, 1988).

Reliability for the JCS was recently assessed in a study conducted with 177 cardiac transplant patients (Jaloweic, 1991). Cronbach alpha coefficients revealed a .91 for total use of coping strategies and a .92 for total effectiveness of the coping strategies used. Reliability for each subscale was assessed, as well, and results are as follows: confrontive .79, evasive .72, optimistic .72, fatalistic .49, emotive .58, palliative .55, supportant .55, and self-reliant .65.

Reliablity coefficients for internal consistency were determined from this study using Cronbach's alpha for the total scale as well as each subscale (See table 1).

Table 1
Reliablity coefficients for JCS

Scale	Cronbach's alpha	
	Usage	Effectiveness
Total JCS Styles	.91	.92
Confrontive	.76	.79
Evasive	.81	.76
Optimistic	.69	.84
Fatalistic	.16	.13
Emotive	.68	.66
Palliative	.53	.54
Supportant	.75	.76
Self-reliant	.69	.61

Quality of Life Index Scale (QLI)

The perceived quality of life was measured using the QLI developed by Padilla and Grant (1985). They originally based their tool on an 8-item Quality of Life Evaluation Scale developed by Presant et al. (Presant, Klahr, & Hogan, 1981). However, following Flanagan's (1982) work and a search for a specific outcome measure for cancer patients undergoing treatment the QLI was developed (Grant, et al., 1992). This tool provides a multidimensional approach to measuring QOL. It describes 4 categories of attributes that are accepted in the quality of life domain. These include physical (items 10, 11, 12, 14, 15, and 16), psychological (items 2, 3, 4, 5, 9, 13, 17, 19, 21, and 22), interpersonal or social well-being (items 1, 6, 7, 8, 18, 20, 28, and 29) and spiritual well-being (items 23, 24, 25, 26, and 27).

The QLI uses a 100 mm linear analogue scale as the response modes in the tool. Each end of the analogue is anchored with words that denote an extreme positive or negative response. There are no numbered markings on the line, instead respondents are asked to place an "X" along the line to indicate the degree to which he/she agrees or disagrees with the statement. The anchor representing the poorest QOL is the zero end of the scale while the anchor representing the best QOL marks the 100 mm point. Scores are obtained by adding all the items in the QLI or the items that pertain to a subscale and dividing by the number of items.

The results of factor analyses of the QLI from various studies affirm the importance of psychological well-being as a primary quality of life dimension. It is represented by a satisfying life, having a good QOL, having fun, feeling happy and enjoying life. Other dimensions include physical well-being (ability to work/carry out usual tasks, fatigue, strength, and feeling healthy), symptoms/side effects (nausea, vomiting, pain, distress, and pain frequency), and nutrition (able to eat, appetite, weight, taste changes).

Content validity and reliability have been outlined in several studies (Padilla, 1992). One such study by Grant et al. (1992) on the measurement of quality of life in bone marrow transplantation survivors supports this as well. The psychometric analysis of this tool revealed content validity of .90. Content validity was measured using several different methods. The first method was development of the instrument by having a panel of experts rate each item. A level of 90% agreement was established for acceptance of the item content. The second method used was multiple regression analysis for predicting overall QOL in survivors. Seven variables were found to be statistically significant predictors of an increased perception of overall QOL. A third measure used the total mean QOL score as the dependent variable. These variables accounted for 83% of the variance of QOL scores. It was also found that psychological well-being consistently accounted for the largest part of the variance in factor structures. Pearson's correlation was used to determine the relationship between individual items of the QOL instrument (all correlations ≤ 0.05). The last measure for validity was using factor analysis to refine the subscales. The factors identified included: psychological well being, physical well being, social concerns, worry, weight concern and fatigue.

Test-retest reliability was done by having a random sample of 46 subjects complete a second QOL survey one week after the initial testing. Pearson's correlation coefficient revealed a strong relationship between responses over time ($r = .71$, $p = < 0.001$). The second measurement was computed for internal consistency using Cronbach's alpha coefficient. This revealed agreement between items and subscales of the instrument (r = .85, p = < 0.01). Subscale alphas ranged from r = .40-.86 for physical well being to psychological well being respectfully.

There have been 9 variations of the scale to measure QOL for various populations but not for the patient population of this study. With the consent of the authors, minor modifications to the instrument were made for applicability to the recipients of the ICD device (see Appendix C). The modifications consisted of the following: the word your was used instead of "family members" in three of the questions; ICD implantation was inserted where "disease or treatment" was; the question regarding sexual problems was left general (no specifics listed out as in the bone marrow transplant tool); and ICD shocks was incorporated in place of "visual changes". One original question was added at the end, to make the tool more specific for this population.

Internal consistency of the 29 quality of life items was determined using Cronbach's alpha. A Cronbach's alpha of 0.899 was obtained for the modified Quality of Life Index scale. For this sample, the standardized item alpha was .911.

Informational Questionnaire

The ICD recipients were also asked to complete an informational questionnaire (see Appendix C) which aided in identifying specific variables related to coping and QOL. One variable of interest was ethnic background. In an article by Marshall (1990) regarding cultural influences on perceived QOL, she states that peoples' cultural beliefs and personal experiences directly influence their appraisal of stimuli confronting the person and their response to them. Age has been discussed earlier, in that people over the age of 50 were less apt to use certain coping strategies. Thus, it will be important, in this study, to identify subjects' age, especially since the average age of ICD implant recipients is 61 (Cardiac Pacemakers, Inc., 1989). Another area of interest is the role of support groups. Many patients who attend support groups benefit from the emotional support and develop a sense of camaraderie. They have similar problems they can share with each other, discuss how they cope to move forward and feel safe to discuss fears and anxieties (Teplitz, Egenes, & Brask, 1990; Badger & Morris, 1989).

Other areas that are of interest are those that have been mentioned in the literature review in which little research has been done. For example, do people who have an ICD for 4 or more years adjust better than those who have had theirs less than 4 years? The number of shocks experienced has been shown to be very distressful. Therefore, does a greater number of shocks decrease a person's level of coping and adaptation and their QOL?

Kalbfleisch, et al. (1989), identified reemployment as a direct contributor to QOL, thus it's relationship in this study was valuable to assess. Also, to aide nurses in their assessment of patients and education they provide, it was beneficial to see if there were particular items that patients found helpful to know prior to implant. Knowledge of these could prepare patients more realistically for what is ahead of them post-implant. This would enable early assistance to strengthen and build successful coping strategies thereby improving the person's QOL.

Pilot Study

After receiving Human Subject Review approval from appropriate institutions, a pilot study was conducted using four subjects. Criteria for inclusion in the pilot study were the same as for the larger study sample. The purpose of the pilot study was to evaluate the effectiveness of the data collection process: clarity of the verbal script, directions for completing the tool, additional questions on the instrument, length of time to complete all questionnaires and data inquiries, as well as the process for obtaining a convenience sample.

Results of the pilot study revealed several findings. One was that careful explanation of how to complete both the JCS and the QLI scale was necessary. Three of the four subjects who participated in the study had missing data on Part B of the JCS. The QLI scale revealed no overall problems in clarity of the questions that were added and/or modified. However, one question (#22) relating to the distress of shocks was found to be not applicable for one subject who had never been shocked before. This was then made as missing data for the data retrieval process in the large study. There were no questions regarding the informational questionnaire.

The pilot study was also used to elicit subjects' thoughts on the convenience of filling out questionnaires in the office versus taking them home. Three of the four subjects felt it would be much easier to complete at home and send the results back to the researcher. One felt it was too lengthy to complete at the office, one did not have his glasses for reading, and one said his hands were too shaky.

As a result of these findings several measures were put in place to increase sample size and return rate. These measures are explained in the following procedure.

Procedure

Subjects meeting the selection criteria were approached by a data collector upon arrival for their follow-up ICD appointment. The data collectors were Registered Nurses working in the approved sites and the researcher. The data collectors proceeded with reading the printed verbal script eliciting subject participation. Once the subject consented to participation they were handed the questionnaire packet, which included a stamped addressed envelope for return of the questionnaire to the researcher. To assure completeness of data, directions for the tools were then verbally reinforced.

As was noted in the pilot study, subjects had some difficulty in completing all questions and parts of the JCS. Thus, to increase return rates, a list of subject names, phone numbers, and identification code numbers was compiled and kept by the data collectors. These were kept confidential and were used strictly for increasing return rate and/or completeness of answering information on the questionnaires. These lists were destroyed upon completion of the data collection process. Throughout the data collection process, the researcher was available by phone to answer any questions subjects encountered while answering the questionnaires. The only risk to patients who participated in this study was the possibility of bringing about anxiety due to answering questions such as, "what is your greatest fear"? However, the subjects had direct contact on an ongoing basis with the data collectors if the need for assistance and support were to arise.

CHAPTER 4

Results

Data Analysis

Data were collected over a 4 month period from December, 1994 to March, 1995. Of 61 patients who met the criteria for the study and were given questionnaires to mail back, 47 returned questionnaires for a 77% return rate. The subjects who sent incomplete questionnaires were called at home to obtain the missing data. However, those who did not complete the QLI scale correctly (N=6) were excluded because there was no objective way to complete the visual analogue scale. Those who answered "never used" on the entire JCS were excluded as well due to perceived misunderstanding of the scale. Of the questionnaires returned, a total of 8 were excluded for a final sample size of 39 subjects.

Characteristics of Subjects

The majority of the sample population were male. Age distribution spanned from 26-68 years with a mean of 61.9. These findings are similar to others presented in the literature, where the majority of ICD implants are males and the average age is 61 years (Cardiac Pacemakers, Inc., 1989). Most subjects were married and felt they had an adequate support system. Years of education ranged from 8-18 with a mean of 13.4. Ethnic background was predominately Caucasian. (See Table 2).

Table 2

Sample Distribution by Sex, Marital Status, Education, and Support Systems

Characteristics	N	%
Sex		
Male	31	79.5%
Female	8	20.5%
Marital Status		
Married	33	84.6%
Separated/Divorced	4	10.3%
Widowed	2	5.1%
Adequate Support Systems	36	92.3%
(N=39)		

The number of years since the subjects original ICD implant was 1-6 years with a mean of 3.15. The surgical method used for implanting the ICD was fairly evenly

Table 3

Distribution of Sample Population by Surgical Method used and Number of Generator Changes since Original Implant

	(N=39)	%
Surgical Method used		
Lead System	10	25.6%
Sternotomy	13	33.3%
Thoracotomy	16	41.0%
Generator Changes		
Yes	16	46.2%
No	21	53.8%
Number of Generator Changes		
None	23	59.0%
One	14	35.9%
Three	2	5.1%

distributed between the 3 types as well as the number of generator changes since implant (See Table 3).

Twenty-five (64.1%) of the subjects reported they attend a support group with varied frequency (See Table 4).

Table 4

Distribution of Sample by Frequency of Support Group Attendance

	(N)	%	Mean
Attend a Support Group			
Yes	25	64.1%	
No	14	35.9%	
How Often Attended			1.54
None	14	35.9%	
1-2x/month	6	15.4%	
every other month	10	25.6%	
4x/year	2	5.2%	
other	7	17.9%	

The data collected from subjects in one ICD support group were identified by a special code to enable the researcher to identify their responses for possible differences and biases, as these participants have contact with the researcher on an ongoing basis. The mean QOL score for those attending the researcher's support group was 71.2 and 69.7 for the other groups. The analysis of variance indicated no significant difference between the two groups (*t* (-.31), *F* = 23, 2-tail prob. = .76).

Data were collected on the number of ICD shocks over the past year. The relationship between length of time since implant, number of generator changes, and number of ICD shocks was compared to subjects perceived QOL. No statistically significant findings were noted (see

Table 5).

Subjects were also asked if they had experienced any sudden cardiac death (SCD) episodes since their ICD implant, and if they would recommend the device to family or friends (See Table 5).

Subjects were asked for information regarding their return to normal activities. There were 14 (35.9%) subjects who were unable to return to work. Of those attending school at the time of implant 100% (N = 2) were able to return.

Table 5

Distribution of Sample by Number of ICD Shocks, SCD's, and Recommendation for Device

	N	%	Mean
ICD Shocks	18	46.2%	1.85
Never	21	53.8%	
1-3	9	23.1%	
4-6	5	12.8%	
7-10	2	5.2%	
>10	2	5.1%	
SCD's			
Yes	7	17.9%	
No	32	82.1%	
Recommend Device			
Yes	38	97.4%	
No	1	2.6%	

Analysis of Research Questions

The main research question examined the relationship between use of the 8 coping strategies as identified by Jalowiec (1987) and QOL in ICD recipients. Three coping strategies (evasive, fatalistic, and emotive) were significantly related to a lower QOL (see Table 6).

Table 6

Distribution of Sample by Coping Styles and QOL

COPING STYLES	r	p<.05
Confrontive	-.03471	.8339
Evasive	-.53997	.0004*
Optimistic	.16309	.3212
Fatalistic	-.61193	.0000*
Emotive	-.60878	.0000*
Palliative	-.25143	.1226
Supportant	.09812	.5523
Self-reliant	-.14234	.3873

N=39,

*p<.05

Analysis of Other Variables

The overall mean QOL score was 68.55 for all the subjects.

Responses to the question, which of the 8 coping strategies are used most often revealed that people use a variety of styles. Optimistic, supportant and self-relient were used most often, and evasive and emotive the least (See Table 7).

In response to the question regarding which of the 8 coping strategies are most effective, it was found that optimistic, supportant, and confrontive were the 3 most effective strategies. It was also noted that evasive and emotive were the least effective coping strategies (See Table 7).

Table 7

Coping Strategies ranked by mean Use and mean Effectiveness

Coping Strategy	M	SD
	Mean Use*	
Optimistic	2.21	.482
Supportant	1.59	.785
Self-Reliant	1.57	.655
Confrontive	1.52	.591
Palliative	1.32	.456
Fatalistic	1.10	.489
Evasive	.99	.563
Emotive	.84	.612
	Mean Effectiveness**	
Optimistic	2.01	.651
Supportant	1.67	.859
Confrontive	1.43	.615
Palliative	1.25	.480
Self-Reliant	1.23	.577
Fatalistic	.80	.470
Evasive	.70	.460
Emotive	.37	.459

Scale range
*0 = never used
1 = seldom used
2 = sometimes used
3 = often used

**0 = not helpful
1 = slightly helpful
2 = fairly helpful
3 = very helpful

The question regarding the differences between types of coping strategies used and the demographic variables of age, sex, marital status, support systems, ethnic background, and level of education were not analyzed because subjects used four or more different coping strategies. All subsequent questions asking for coping strategy comparisons were also not analyzed.

No significant relationships were seen between length of time since implant, number of surgeries for generator changes and ICD shocks (see Table 8).

Table 8

Pearson correlation coeffients for ICD variables and QOL

Subgroup	r	p
Length of Time Since Implant	.55	.45
Number of Surgeries for Generator Changes	.46	.32
ICD Shocks	.21	.20

(N=39)

In looking at the average scores for all 8 coping strategies in subjects who received shocks (N=18), the 4 most frequently used coping strategies were optimistic (2.15 average), supportant (1.62 average), self-reliant (1.38 average), and confrontive (1.36 average).

Those who attended support groups, returned to work and had restrictions placed on them did not differ in their reported QOL (see Table 9).

Thirty-eight subjects (97%) said they would recommend the device to family or friends. Due to lack of variance for the 1 subject a t-test could not be run to assess the difference for QOL scores. There was also an insignificant number of female subjects to do a comparison on sex.

Table 9

Differences Between Subgroups Listed and QOL

Subgroup	t value	degrees of freedom	2-tail probability
Attendance/non-attendance at Support Group	.84*	18.5*	.414*
Able to Return Work	1.25	22.0	.224
Restrictions	-1.43	37.0	.163

(N=39)
(*separate variance)

Summary of Responses to Open Ended Questions

The first question was: What has been your main problem since your ICD implant. Of the 32 people who responded, 11 had psychosocial concerns (e.g., fear of death, anticipation of ICD shocks, stress, depression, and family concerns). Ten people stated it was the bulkiness and discomfort of the generator. Other problems included: physical symptoms (N=6), such as other illnesses, weakness, and pain; knowledge (N=4) regarding rhythm, SCD's, ICD generator and pacemakers; and inability to drive (N=1).

The second question was: What was the most helpful information to receive before your implant. Most people (N=13) felt the information they were given was great, but did not list any examples. Of the 19 who shared examples, 13 wanted more information about the device (e.g., why it was needed, how shocks feel, and what to expect before and after implant). Five people said it would have been helpful talking with another ICD patient and 1 person said knowing the restrictions (e.g., no driving).

The third question was: What the most helpful information was to receive after implantation. The majority of the subjects (N = 8) stated technical information (e.g., shocks, rejection, malfunctions, and what things to avoid to limit shocks). Five subjects stated factual truth and information from the health care team, 1 stated knowing of a facility closer to home to care for the device, 5 stated encouragement to carry on a normal life, and 6 stated knowing of support groups and being able to talk to others who have an ICD.

The fourth question was: What were the most common restrictions placed on your activities. Results revealed that 23 (59%) of the subjects had restrictions placed on them and their activities. Eleven of these subjects stated they were restricted in physical activities (e.g., weight lifting, scuba diving, etc.). Five stated no further driving, 3 could not return to work, 2 stated avoiding magnetic fields, 1 was told to avoid cold weather, and 1 was not able to operate heavy equipment any longer.

The fifth question was: How has your life changed since your implant. Thirty-two subjects responded with several different responses. Thirteen subjects stated their physical activity had decreased, and 7 felt they were more conscious of their health and QOL. Other responses included: psychosocial concerns (e.g. overprotective family, emotional, and mood) (N=3), no changes or improved (N=3), limitations on driving privileges (N=2), and less financially secure (N=1).

The last question was: What is the greatest fear about your ICD device. The majority of subjects (N=21) stated device malfunction (e.g., not firing when needed, or firing inappropriately and too much). Other responses included: where they get shocked (N=5) (e.g., out in public or on vacation), having to be shocked (N=3), driving will be restricted by law (N=1), and falling may break device (N=1).

CHAPTER 5

Discussion

Discussion

Use of the evasive, fatalistic, and emotive coping styles revealed a significant relationship to a lower QOL. These 3 styles are somewhat related in that subjects see themselves as needing to avoid or ignore problems (evasive), having little control (fatalistic), and needing to ventilate feelings (emotive). In Kuiper and Nyamathi's study (1991) these three coping strategies were used the least. (It should be noted, however, that the fatalistic coping subscale had a low reliability in this study.)

Optimistic, supportant, and self-reliant were the strategies most often used. Optimistic, supportant, and confrontive were identified as the most effective strategies. The multidimensional JCS (1987) has been limited in use for this particular population of subjects, thus making comparisons difficult. However, it was interesting to note that the 3 strategies most often used and determined as effective were consistent with those found in other studies.

Kuiper and Nyamathi (1991) noted in their study that optimism, confrontive and supportant coping styles were most frequently used by ICD patients. Another study looking at long-term cancer survivors (Halstead & Fernsler, 1994) revealed that subjects rated optimistic, supportant, and confrontive as their most often used and effective strategies. Scherck (1992) found in her study of acute myocardial infarction patients that they also used various coping strategies. Those strategies contributing the most to total coping efforts were optimistic, confrontive, self-reliant, and supportant.

It appears then that most subjects utilize optimistic and confrontive strategies in their repertoire of coping efforts. These 2 coping strategies are positive in nature. They are behaviors in which subjects are seeking out information and setting up different plans and compromises to deal with stressful events in life.

The results of this study also revealed common fears ICD recipients feel regarding their ICD. The fear of greatest concern was of the ICD malfunctioning (firing too much, not firing when needed or inappropriately), which has also been noted in the literature.

No significant relationship with attending a support group was identified in this study. This contradicts findings found in many other studies done on the impact of support groups (Teplitz, Egenes, & Brask, 1990; Badger & Morris, 1989; DeBasio & Rodenhausen, 1984).

There were no statistically significant findings in whether a return to work or school was associated with a higher QOL. This may have been due in part to the population of subjects surveyed. As noted in the study Kalbfleisch, et al. (1989) did on reemployment and QOL the only significant difference they documented between employed and unemployed patients was their age and education. This suggests that the ICD device can assist in facilitating a patient's resumption of preemployment capabilities, thus increasing one's QOL.

Druss and Kornfeld (1967) noted in their study of SCD survivors that many reported activity restrictions beyond those that were medically necessary. In this study, restrictions on activities were assessed but no statistically significant differences were noted between them and QOL. The majority of the subjects with restrictions stated they had physical limitations (e.g., weight lifting, scuba diving, etc.) placed on them.

As stated earlier, there was only one patient who would not recommend the ICD device to others. Most people feel a sense of security with having the device (Pycha, Gulledge, Hutzler, Kadri, & Maloney, 1986), but do have lingering fears.

It was interesting to note that the findings for the open ended questions, "main problem since implant", and "has their life changed since implant", were consistent with previous studies done on ICD recipients. It has been noted throughout the literature that there are many psychological sequlea that erupt due to SCD events and ICD implantation (Morris, Badger, Chmielewski, Berger, & Goldberg, 1991; Pycha, Calabrese, Gulledge, & Maloney, 1990; Pycha, Gulledge, Hutzler, Kadri, & Maloney, 1988; Vlay, Olson, Fricchione, & Friedman, 1989; & Jenkins, Dunbar, Hawthorne, 1994).

In this study subjects identified a variety of psychological concerns (e.g., fear of death, anticipation of ICD shocks, stress, depression and family concerns). They also identified discomfort from the generator, physical symptoms, knowledge deficits, and the inability to drive. When expressing how their life had changed since implant, subjects identified a decrease in physical activity, increased consciousness of their health and QOL, psychological concerns (overprotective family, emotional, and moodiness), limitations on driving privileges, less financially secure, and no changes in life-style or that life-style had improved.

Subjects' responses to the questions of "the most helpful information received before and after implant" revealed that subjects wanted more technical information about the device and why it was needed. They also felt it would have been helpful to have spoken with other ICD recipients before implant, receive information on facilities closer to home for follow-up, receive encouragement to carry on a normal life, and to know about support groups providing the chance to talk to others with an ICD device. These findings were similar to a recent study conducted by Davis, Dunbar, Jenkins, Hawthorne, & Purcell (1995) on the advice from ICD patients and families.

Limitations

There are several limitations that should be taken into account prior to any generalizations of the study findings. One limiting factor was the nature of the sample population. The sample was moderate in size and fairly homogeneous, consisting of middle-aged, white males from the midwest. Several subjects sent incomplete questionnaires which were not included in the study, and there were many ICD patients who were not seen due to changes in office schedules. If they had been included, the results of the study may have been different.

The nature of the JCS may have contributed to several limiting factors of the study. One point to consider is the stressor identified on the top of the scale, "ICD implantation". In talking with numerous subjects to complete questionnaires, this was identified as a confusing factor. They did not understand if they should answer the scale in retrospect of how they felt in the past when they initially needed the ICD or for events in general. The length of the questionnaire and having two parts (use and effectiveness) posed problems with completeness. Twenty-one of the 39 subjects included in the study needed to be called to complete missed questions on the JCS. This may have resulted in bias due to subjects reporting answers from a perception of an ideal self or to give answers to how they think the researcher was wanting them to answer. Some of the items may have been perceived as less desirable or less attractive (e.g., get mad and let off steam, expected worst that could happen, took out your tensions on someone else, did something impulsive or risky, ignore problem, or took medications to reduce tension) due to religious beliefs or other factors as mentioned. These points may have contributed to the 2 subjects who answered zero (or "never used") on the entire scale and were excluded. The revised JCS also has 8 different coping strategies to identify multidimensional domains. This made it impossible to answer several of the research questions that were looking for relationships and effects between particular coping strategies and other variables.

Overall, subjects had little difficulty in completing the revised QLI scale. There were less than seven subjects who were excluded due to incompleteness of the scale. The scale was a visual analogue scale, thus impossible to objectively complete through a telephone call. One observation was several subjects said they have never received a shock from their ICD. However, only 1 subject was identified as never receiving a shock and excluded from question number 21, "do you have any distress from ICD shocks (the device firing)". The people who answered this question possibly answered it related to anticipation and fear of shock and may have skewed the results.

Summary of Results

The major results of this study revealed that there were few statistically significant findings in the area of coping strategies and QOL. However, the fact that similar coping strategies are used among different patient populations was noted. It also confirmed the same fears and anxieties and overall positive QOL that have been noted in the literature for ICD recipients (Bainger & Fernsler, 1995). The subjects in this study rated a fairly high QOL (range 0 - 100) which compares to 71.3 for bone marrow transplant patients noted in the article published by Grant et al (1992).

Conclusions

The impact of ICD therapy on survival from SCD is positive and rapidly becoming a common treatment option for patients (Teplitz, Egenes, & Braski, 1990). It has also been noted that patients going through the decision to implant and actual implant of ICD devices experience various amounts of stress and need for information. How ICD recipients cope with this stress and how they perceive their QOL was evaluated in this study. Overall the QOL perceived by this population was high. Direct relationships for specific coping strategies and QOL scores were not identified due to the various coping strategies subjects used. Patients who seem to be using ineffective coping strategies should be encouraged to use alternative coping strategies (e.g., optimistic and supportant). The results of this study also support the usefulness of assessing social/support systems and providing timely education.

Implications/Application for Nursing Practice

Betty Neuman's conceptual framework for nursing provided the theoretical framework for this study. The concept that individuals are holistic, open systems interacting with stressors in their environment is essential. Individuals are continually exposed to stressors (both noxious and beneficial) and need to respond or adapt to these to maintain a system of harmony and wellness. As revealed in this study and in the literature, there are many stressors ICD recipients face and must adapt to in order to build and store the energy that is needed for a state of wellness.

Although there were no direct relationships established between a specific coping strategy and a high rating of QOL, certain directions for care of ICD patients can be extrapolated. When reviewing the three levels of prevention (see Appendix A), it is evident that identifying realistic goals with the patient (meeting basic physical needs, etc.), developing strategies for life-style changes, assisting with psychosocial needs of patients and family members, and providing a basis for patient education are major areas for nursing focus.

Education/Administration

Nursing assessments, interventions, and goals in the care of the ICD patients should be directed at maintaining, attaining or regaining a state of wellness. Nurses should focus their holistic assessments on patients coping skills and strategies that were successful and incorporate techniques of the supportant and optimistic coping styles (e.g., looking at the problem objectively, seek information, and set up a plan of action) in their goal setting. Nurses can work with these behaviors and encourage patients to build upon them, thus strengthening their flexible and normal lines of defense and maintaining a state of wellness (Neuman, 1989).

As related in this study, ICD patients have many psychological and social needs, as well as issues and concerns about the device itself. It would be helpful to provide as much information and education as possible on the device (e.g., video, pamphlets, etc.). It may also be of benefit for patients to talk with another patient who is living with an ICD to see how they have adapted. Providing information on restrictions and body image changes may be helpful as well. Spending time with patients to let them verbalize fears, frustrations, and questions will be very important. Post implant it will be necessary to provide information on necessary follow-up physician appointments, as well as, how to access phone numbers for other centers that can do follow-up checks if people want to continue to travel. It will be crucial to convey to patients to carry on a normal life and activities. That the ICD is there as a back up if their heart should need it, but it should not limit most of their activities. Some patients may find it psychologically beneficial to build activity and endurance through a monitored cardiac rehab program before going out on their own. Encouragement to attend ICD support groups should also be a recommendation for prevention and adaptation to the ICD as well.

Recommendations

This study should be repeated using a more definitive coping scale. A coping scale specific to the cardiac population needs to be developed. The revised QLI scale should also be used again with this population of patients in order to make comparisons for ratings of QOL. Comparisons of new implants (< 6 months) to those who have had the device greater than 1 - 2 years should also be made. There may be adjustments and adaptations over time that enable people to cope at the level they do. Mailing out questionnaires may also help to increase both sample size and involvement by a more diverse group of subjects who may not have had the chance to get involved in this study.

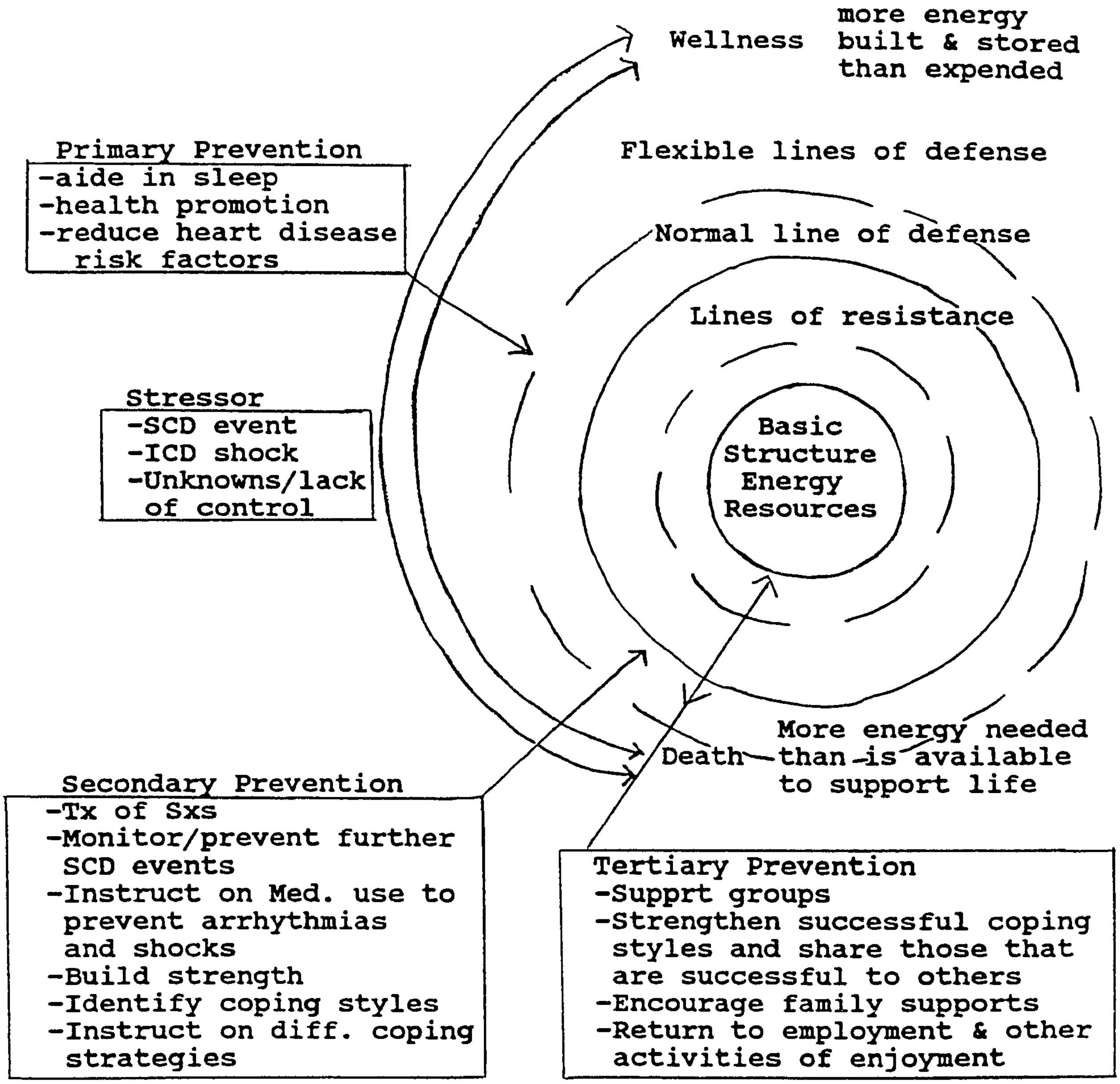
There have been many indications in the literature (Kuiper & Nyamathi, 1991; & Teplitz, 1991) that families have great difficulty adjusting to these life changes and potential losses as well as ICD recipients. In this study, the question on the QLI scale about, "how distressing has your illness and ICD implant been on your family" rated with a mean score of less than 50. This is comparatively lower than other scores on how the subject feels about their QOL. A study regarding families coping, fears and adaptations to these stressful life events would be very beneficial in working with the family unit. Referrals to home health care agencies, cardiac rehab, CPR courses, and support groups may help to reduce anxiety of patients and family members and assist with making necessary life-style changes.

It has also been noted that ICD recipients have a need to talk about events leading to implant, such as their SCD, as well as post-implant events (e.g., shocks, device changes). Research in this area may also be beneficial in reducing anxiety and fear in both recipients and their families.

APPENDICES

APPENDIX A

Conceptual Framework: Effect of Coping Strategies



Neuman's System Model; adapted for the wellness-illness continuum of ICD patients.

APPENDIX B

Study # _______

JALOWIEC COPING SCALE

This questionnaire is about how you cope with stress and tension, and what you do to handle stressful situations. In particular, I am interested in how you have coped with the stress of:

ICD IMPLANTATION

This questionnaire lists many different ways of coping with stress. Some people use a lot of different coping methods; some people use only a few.

You will be asked two questions about each different way of coping with stress:

Part A

How often have you used that coping method to handle the stress listed above?

For each coping method listed, circle one number in Part A to show how often you have used that method to cope with the stress listed above. The meaning of the numbers in Part A is as follows:

0 = never used
1 = seldom used
2 = sometimes used
3 = often used

Part B

If you have used that coping method, how helpful was it in dealing with that stress?

For each coping method that you have used, circle a number in Part B to show how helpful that method was in coping with the stress listed above. The meaning of the numbers in Part B is as follows:

0 = not helpful
1 = slightly helpful
2 = fairly helpful
3 = very helpful

If you did not use a particular coping method, then do not circle any number in Part B for that coping method.

COPING METHODS	Part A How often have you used each coping method?				Part B If you have used that coping method, how helpful was it?			
	Never Used	Seldom Used	Sometimes Used	Often Used	Not Helpful	Slightly Helpful	Fairly Helpful	Very Helpful
1. Worried about the problem	0	1	2	3	0	1	2	3
2. Hoped that things would get better	0	1	2	3	0	1	2	3
3. Ate or smoked more than usual	0	1	2	3	0	1	2	3
4. Thought out different ways to handle the situation	0	1	2	3	0	1	2	3
5. Told yourself that things could be much worse	0	1	2	3	0	1	2	3
6. Exercised or did some physical activity	0	1	2	3	0	1	2	3
7. Tried to get away from the problem for a while	0	1	2	3	0	1	2	3
8. Got mad and let off steam	0	1	2	3	0	1	2	3
9. Expected the worst that could happen	0	1	2	3	0	1	2	3
10. Tried to put the problem out of your mind and think of something else	0	1	2	3	0	1	2	3
11. Talked the problem over with family or friends	0	1	2	3	0	1	2	3
12. Accepted the situation because very little could be done	0	1	2	3	0	1	2	3
13. Tried to look at the problem objectively and see all sides	0	1	2	3	0	1	2	3
14. Daydreamed about a better life	0	1	2	3	0	1	2	3
15. Talked the problem over with a professional person (such as a doctor, nurse, minister, teacher, counselor)	0	1	2	3	0	1	2	3
16. Tried to keep the situation under control	0	1	2	3	0	1	2	3
17. Prayed or put your trust in God	0	1	2	3	0	1	2	3
18. Tried to get out of the situation	0	1	2	3	0	1	2	3
19. Kept your feelings to yourself	0	1	2	3	0	1	2	3
20. Told yourself that the problem was someone else's fault	0	1	2	3	0	1	2	3
21. Waited to see what would happen	0	1	2	3	0	1	2	3
22. Wanted to be alone to think things out	0	1	2	3	0	1	2	3
23. Resigned yourself to the situation because things looked hopeless	0	1	2	3	0	1	2	3

COPING METHODS	Part A How often have you used each coping method?				Part B If you have used that coping method, how helpful was it?			
	Never Used	Seldom Used	Sometimes Used	Often Used	Not Helpful	Slightly Helpful	Fairly Helpful	Very Helpful
24. Took out your tensions on someone else	0	1	2	3	0	1	2	3
25. Tried to change the situation	0	1	2	3	0	1	2	3
26. Used relaxation techniques	0	1	2	3	0	1	2	3
27. Tried to find out more about the problem	0	1	2	3	0	1	2	3
28. Slept more than usual	0	1	2	3	0	1	2	3
29. Tried to handle things one step at a time	0	1	2	3	0	1	2	3
30. Tried to keep your life as normal as possible and not let the problem interfere	0	1	2	3	0	1	2	3
31. Thought about how you had handled other problems in the past	0	1	2	3	0	1	2	3
32. Told yourself not to worry because everything would work out fine	0	1	2	3	0	1	2	3
33. Tried to work out a compromise	0	1	2	3	0	1	2	3
34. Took a drink to make yourself feel better	0	1	2	3	0	1	2	3
35. Let time take care of the problem	0	1	2	3	0	1	2	3
36. Tried to distract yourself by doing something that you enjoy	0	1	2	3	0	1	2	3
37. Told yourself that you could handle anything no matter how hard	0	1	2	3	0	1	2	3
38. Set up a plan of action	0	1	2	3	0	1	2	3
39. Tried to keep a sense of humor	0	1	2	3	0	1	2	3
40. Put off facing up to the problem	0	1	2	3	0	1	2	3
41. Tried to keep your feelings under control	0	1	2	3	0	1	2	3
42. Talked the problem over with someone who had been in a similar situation	0	1	2	3	0	1	2	3
43. Practiced in your mind what had to be done	0	1	2	3	0	1	2	3
44. Tried to keep busy	0	1	2	3	0	1	2	3
45. Learned something new in order to deal with the problem	0	1	2	3	0	1	2	3
46. Did something impulsive or risky that you would not usually do	0	1	2	3	0	1	2	3

COPING METHODS	Part A How often have you used each coping method?				Part B If you have used that coping method, how helpful was it?			
	Never Used	Seldom Used	Sometimes Used	Often Used	Not Helpful	Slightly Helpful	Fairly Helpful	Very Helpful
47. Thought about the good things in your life	0	1	2	3	0	1	2	3
48. Tried to ignore or avoid the problem	0	1	2	3	0	1	2	3
49. Compared yourself with other people who were in the same situation	0	1	2	3	0	1	2	3
50. Tried to think positively	0	1	2	3	0	1	2	3
51. Blamed yourself for getting into such a situation	0	1	2	3	0	1	2	3
52. Preferred to work things out yourself	0	1	2	3	0	1	2	3
53. Took medications to reduce tension	0	1	2	3	0	1	2	3
54. Tried to see the good side of the situation	0	1	2	3	0	1	2	3
55. Told yourself that this problem was really not that important	0	1	2	3	0	1	2	3
56. Avoided being with people	0	1	2	3	0	1	2	3
57. Tried to improve yourself in some way so you could handle the situation better	0	1	2	3	0	1	2	3
58. Wished that the problem would go away	0	1	2	3	0	1	2	3
59. Depended on others to help you out	0	1	2	3	0	1	2	3
60. Told yourself that you were just having some bad luck	0	1	2	3	0	1	2	3

If there are any other things you did to handle the stress mentioned at the beginning, that are not on this list, please write those coping methods in the spaces below. Then circle how often you have used each coping method, and how helpful each coping method has been.

61.		1	2	3	0	1	2	3
62.		1	2	3	0	1	2	3
63.		1	2	3	0	1	2	3

Revised 7/90

APPENDIX C

QUALITY OF LIFE INDEX TOOL
For ICD Recipients

Below are a number of questions pertaining to your well being. PLEASE ANSWER SPONTANEOUSLY. DO NOT THINK TOO LONG ABOUT YOUR ANSWERS. Please make an "X" on the line that best shows what is happening to you at present.

BELOW IS AN EXAMPLE WHICH MAY HELP YOU IN RESPONDING TO THE QUESTIONNAIRE.

How do you feel about your ability to concentrate?

cannot concentrate at all __________________________X___________ can concentrate extremely well

The "X" on the line indicates you are able to concentrate but not 100%

---

1. How easy or difficult is it to adjust to your ICD implantation?

very difficult ____ very easy

2. Do you worry about the cost of your medical care?

not at all ____ a great deal

3. How useful do you feel?

not at all ____ extremely useful

4. How satisfying is your life?

not at all satisfying ____ extremely satisfying

5. How much happiness do you feel?

none at all ____ a great deal

6. Is the amount of affection you give and receive sufficient to meet your needs?

not at all ____ completely

7. Is your ICD implant interfering with your personal relationships?

not at all ____ a great deal

8. How much are you able to do the things you like to do such as watch TV, read, garden, listen to music, etc.?

not at all ____ a great deal

9. How is your present ability to pay attention to what's happening?

extremely poor ____ excellent

10. How much strength do you have?

none at all ____ a great deal

11. Do you tire easily?

not at all ____ a great deal

12. Is the amount of time you sleep sufficient to meet your needs?

not at all ____ completely

13. How good is the quality of your life?

extremely poor ____ excellent

14. Do you currently have pain from an illness or other cause?

no pain ____ a great deal

15. How much of an appetite do you have?

none ____ more than usual

16. Do you have any sexual problems?

no problem ____ severe problem

17. Are you worried about unfinished business?

not at all ____ extremely

18. Is the support you receive from others sufficient to meet your needs?

not at all sufficient ______________________________ completely sufficient

19. Do you feel like you are in control of things in your life?

not at all ______________________________ completely

20. How distressing has your illness and ICD implant been for your family?

not at all ______________________________ a great deal

21. Do you have any distress from ICD shocks (the device firing)?

none at all ______________________________ a great deal

22. How much enjoyment are you getting out of life?

none ______________________________ a great deal

23. Do you sense a purpose/mission for your life or a reason for being alive?

none at all ______________________________ a great deal

24. Do you have a sense of inner peace?

none at all ______________________________ a great deal

25. How important to you is your participation in spiritual or religious activities such as praying or going to services?

not at all ______________________________ a great deal

26. How much support does your faith give you?

none at all ______________________________ a great deal

27. How hopeful do you feel?

not at all hopeful ______________________________ very hopeful

28. How satisfied are you with your current appearance?

completely dissatisfied ________________________________ completely satisfied

29. Are you concerned about being shocked by your ICD device while out in public?

not at all concerned ________________________________ very concerned

APPENDIX D

Informational Questionnaire

Please circle the appropriate information (optional):

1. Gender: a. Male b. Female

2. Marital status:
   a. Single c. Separated/divorced
   b. Married d. Widowed

3. Do you have an adequate support system/person?
   a. Yes b. No

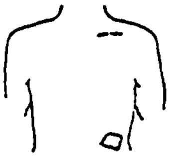
4. What is your age in years? ____________

5. Ethnic Background:
   a. Caucasian d. Oriental
   b. Black e. American Indian
   c. Hispanic f. Other ____________

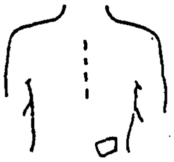
6. Number of years of school completed (for example, graduated from high school = 12 years)? ____________

7. How many years has it been since your original ICD implant? ________

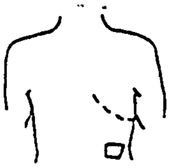
8. What surgical method was used to put your ICD device in you? (check one)



a. _____



b. _____



c. _____

9. Have you had any generator changes since implant?
   a. Yes b. No

   If yes, how many? _______

10. Do you attend a support group for ICD recipients?
    a. Yes b. No

    If yes, how often do you attend?
    a. 1 - 2 x/month c. Four times a year
    b. Every other month d. Other________

11. How many ICD shocks (firings) have you had over the past year?
    a. Never
    b. 1 - 3
    c. 4 - 6
    d. 7 - 10
    e. More than 10

12. Have you been able to return to work?
    a. Yes
    b. No
    c. Not applicable

13. Have you been able to return to school?
    a. Yes
    b. No
    c. Not applicable

14. Have you had any sudden cardiac death episodes since your implant?
    a. Yes
    b. No

15. What has been your main problem since your ICD implant?

____

____

16. What would have been the most helpful information to receive before your implant?

____

____

17. What would have been the most helpful information to receive after your implant?

____

____

18. Have there been any restrictions placed on you and your activities?

Yes __________ No __________

If so, what are they? ______________________________________

____

19. Would you recommend ICD implantation to a family member or a close friend?

Yes __________ No __________

20. How has your life changed since your implant?

____

____

____

21. What is your greatest fear about your ICD device?

____

____

____

Appendix E

Verbal Script

Hello, Mr., Mrs., or Ms. My name is Jacquie Oliai and I am a graduate student from the Master's of Nursing program at Grand Valley State University in Grand Rapids. I am currently working on a research project involving recipients of Implantable Cardioverter Defibrillators (ICDs).

I am interested in studying how patients, such as yourself, cope with having an ICD and how this affects their lives. The goal is to improve care and education to patients who require the implantation of this device in the future.

Your participation involves filling out 2 questionnaires and an information sheet. The first questionnaire is the Jalowiec Coping Scale which looks at a variety of coping methods people use to deal with a variety of events in life. The second questionnaire looks at quality of life as you see it. The third questionnaire asks for information about you (such as age, number of years you have had ICD, etc.). It will take approximately one hour to complete all three questionnaires.

All information you share through the questionnaires will be strictly confidential, and any reports of the study will reveal only grouped information. Your name will not be placed on the questionnaire, and you will be identified only by a code number. However, I will need your name and phone number so that I may call you if there are questions that are not completed. The name and phone number list will be destroyed once the questionnaire is complete. There are no expected risks or costs for your participation; it is completely voluntary; and your care will not be affected in any way, regardless of your decision.

Should you decide to participate, please complete the questionnaires, but do not put your name on them. You may receive results of the study by writing your name and address on a separate piece of paper or index card and enclose it with your questionnaires. Return all items to me in the postage paid envelope within two weeks.

If you have any questions or concerns I can be reached by phone at (Work) 616-774-7345, or (Home) 616-459-3927.

Would you be interested in participating in the study?

Appendix F

Verbal Script for Assistants

Hello, Mr., Mrs., or Ms. I am assisting Jacquie Oliai, a graduate student from the Master's of Nursing program at Grand Valley State University in Grand Rapids. She is currently working on a research project involving recipients of Implantable Cardioverter Defibrillators (ICDs).

She is interested in studying how patients, such as yourself, cope with having an ICD and how this affects their lives. The goal is to improve care and education to patients who require the implantation of this device in the future.

Your participation involves filling out 2 questionnaires and an information sheet. The first questionnaire is the Jalowiec Coping Scale which looks at a variety of coping methods people use to deal with a variety of events in life. The second questionnaire looks at quality of life as you see it. The third questionnaire asks for information about you (such as age, number of years you have had ICD, etc.). It will take approximately one hour to complete all three questionnaires.

All information you share through the questionnaires will be strictly confidential, and any reports of the study will reveal only grouped information. Your name will not be placed on the questionnaire, and you will be identified only by a code number. However, she will need your name and phone number so that she may call you if there are questions that are not completed. The name and phone number list will be destroyed once the questionnaire is complete. There are no expected risks or costs for your participation; it is completely voluntary; and your care will not be affected in any way, regardless of your decision.

Should you decide to participate, please complete the questionnaires, but do not put your name on them. You may receive results of the study by writing your name and address on a separate piece of paper or index card and enclose it with your questionnaires. Return all items to Jacquie in the postage paid envelope within two weeks.

If you have any questions or concerns Jacquie can be reached by phone at (Work) 616-774-7345, or (Home) 616-459-3927.

Would you be interested in participating in the study? If yes, proceed with handing them the questionnaire packet with postage paid envelope. Record patient name, phone number, and questionnaire packet number on log sheet. If no, thank them for their time.

Appendix G

Dear ICD Recipient:

My name is Jacquie Oliai and I am a graduate student in the Master's of Nursing program at Grand Valley State University in Grand Rapids. I am currently working on a research project involving recipients of Implantable Cardioverter Defibrillators (ICDs).

I am interested in studying how patients, such as yourself, cope with having an ICD and how this affects their lives. The goal is to improve care and education to patients who require the implantation of this device in the future.

Your participation involves filling out 2 questionnaires and an information sheet. The first questionnaire is the Jalowiec Coping Scale which looks at a variety of coping methods people use to deal with a variety of events in life. The second questionnaire looks at quality of life as you see it. The third questionnaire asks for information about you (such as age, number of years you have had ICD, etc.). It will take approximately one hour to complete all three questionnaires.

All information you share through the questionnaires will be strictly confidential, and any reports of the study will reveal only grouped information. Your name will not be placed on the questionnaire, and you will be identified only by a code number. However, I will need your name and phone number so that I may call you if there are questions that are not completed. The name and phone number list will be destroyed once the questionnaire is complete. There are no expected risks or costs for your participation; it is completely voluntary; and your care will not be affected in any way, regardless of your decision.

Should you decide to participate, please complete the questionnaires, but do not put your name on them. You may receive results of the study by writing your name and address on a separate piece of paper or index card and enclose it with your questionnaires. Return all items to me in the postage paid envelope within two weeks.

If you have any questions or concerns I can be reached by phone at (Work) 616-774-7345, or (Home) 616-459-3927. Completed packets may be sent to Jacquie Oliai, 524 Glenwood SE, Grand Rapids, MI 49506. Thank you for considering my request.

Sincerely,

Jacquie Oliai, RN

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