LIVING WITH AN IMPLANTABLE CARDIOVERTER DEFIBRILLATOR: IMPACT OF PERCEPTIONS ON PSYCHOSOCIAL WELL-BEING

by

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ABSTRACT

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Under the Supervision of Dr. Julia Snethen

Background: An Implantable Cardioverter Defibrillator (ICD) is an effective intervention for individuals at risk for sudden cardiac arrest. Uncertainty and lack of support impacts acceptance and adjustment to living with an ICD. The primary aim of this study was to examine the associations between uncertainty and social facilitation with the psychosocial well-being of adults living with an ICD.

Methods: This study employed a quantitative exploratory-descriptive design with a convenience sample of participants (N=100). A 91-item survey was distributed virtually. The instruments included a patient characteristics questionnaire and the Florida Patient Acceptance Survey (FPAS) to measure uncertainty, the Multidimensional Scale of Perceived Social Support (MSPSS) to measure social facilitation, and the Psychological Well-Being Scale (PWB) to measure psychosocial well-being.

Results: Psychosocial well-being was predicted by ICD shocks (B = -7.48, p = .004), reason for implant (B = 12.43, p = .05), device-related distress (B =.61, p = <.001), return to life (B = .68, p = <.001), overall ICD acceptance (B =.91, p = <.001), and social facilitation (B = 14.20, p = <.001). Age significantly predicted psychosocial well-being, but gender was not significant.

Conclusions: This study demonstrates the importance of identifying factors that influence psychosocial well-being for individuals living with an ICD. A biopsychosocial approach to care

provision is needed to support adjustment to the device. Further research is needed on the psychological impact of living with an ICD.

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To Jim, Natalie, and Nick

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LIST OF ABBREVIATIONS

ACC	American College of Cardiology
AHA	American Heart Association
APA	American Psychiatric Association
ARVD	Arrhythmogenic Right Ventricular Dysplasia
CAD	Coronary Artery Disease
CDC	Centers for Disease Control and Prevention
CMS	Center for Medicare and Medicaid Services
CVD	Cardiovascular Disease
DFT	Defibrillation Threshold
DHHS	Department of Health and Human Services
DOT	U.S. Department of Transportation
ERI	Elective Replacement Indication
EOL	End of Life
FIFAS	Federal Interagency Forum on Aging-Related Statistics
FPAS	Florida Patient Acceptance Scale
HCM	Hypertrophic Cardiomyopathy
HRQoL	Health-Related Quality of Life
ICD	Implantable Cardioverter Defibrillator
IRB	Institutional Review Board
JHNEBP	Johns Hopkins Nursing Evidence-Based Practice Model
MI	Myocardial Infarction
MSPSS	Multidimensional Scale of Perceived Social Support

NIH	National Institutes of Health
PTSD	Post-Traumatic Stress Disorder
PWB	Psychological Well-being Scale
SCA	Sudden Cardiac Arrest
SCD	Sudden Cardiac Death
SDOH	Social Determinants of Health
Type A	Type A for Driven Personality
Type B	Type B for Relaxed Personality
Type D	Type D for Distressed Personality
VF	Ventricular Fibrillation
VT	Ventricular Tachycardia

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“To heal is to touch with love that which we previously touched with fear.”
— Stephen Levine

“Compassion asks us to go where it hurts, to enter into the places of pain, to share in brokenness, fear, confusion, and anguish. Compassion challenges us to cry out with those in misery, to mourn with those who are lonely, to weep with those in tears. Compassion requires us to be weak with the weak, vulnerable with the vulnerable, and powerless with the powerless. Compassion means full immersion in the condition of being human." ~Henri Nouwen

Chapter One: Introduction to the Problem

The American Heart Association (AHA) (2017) has projected approximately 40% of adults in the US will have cardiovascular disease by 2035. Unfortunately, cardiovascular disease places adults at risk for having a cardiac arrest. Sudden cardiac arrest (SCA) has been attributed to over 360,000 deaths in 2016. Advances in medical science and resuscitation improved SCA survival rates resulting in people living longer with chronic cardiovascular disease (Kremers et al., 2013; AHA, 2017). As cardiovascular disease rates increase, the costs related to managing the chronic condition rises, totaling $555 billion in 2016. Future projections for cardiovascular disease expenditures are $1.1 trillion by 2035, making it the costliest disease in the United States (AHA, 2017).

One strategy for improving cardiovascular disease outcomes while decreasing costs is to improve individuals' ability to self-manage their condition. Incorporating self-management into a cardiovascular plan of care requires ensuring that individuals have the confidence to effectively manage their chronic condition (Department of Health and Human Services [DHHS], 2010; Vellone et. al., 2016). Improving confidence to effectively self-manage and adjust to living with a chronic cardiovascular condition is influenced by individuals' experiences with current health status, perception of life situations, personal beliefs, and social support (Audulv et al., 2012; Mead et al., 2010; Schulman-Green et al., 2016).

Background

An Implantable Cardioverter Defibrillator (ICD) is a common and effective intervention for individuals with chronic cardiovascular conditions at risk for sudden cardiac arrest (SCA) (Al-Khatib et al., 2018; Moss et al., 1996; National Institutes of Health [NIH], 2021; Zipes et al., 2006). Historically, ICDs were implanted for secondary prevention as a last resort following an

SCA (Klein & Nisam, 2015). Continuous improvements in technology of the device, leads, therapies, and programming have occurred since the first ICD was implanted 40 years ago (Al-Khatib et al., 2018; Zipes et al., 2006). The advancement of ICD technology improved delivery of therapies and ease of implant. Subsequent studies showed efficacy in expansion of implant criteria to reduce Sudden Cardiac Death (SCD). For this reason, primary prevention criteria for those at risk of SCA were adopted in the early 2000s (Zipes et al., 2006). The new criteria influenced a rapid and sustained rise in annual implant numbers: up to 300,000 within the United States (Al-Khatib et al., 2017).

Prevalence

A mandatory national registry was established in the United States in 2005 to monitor data on implants, complications, and comorbidities. From 2005 to 2011, the registry logged over 850,000 ICD cases. Trends disclosed approximately 12,500 monthly implants from 2010 and 2011, the majority (74%) for primary prevention. The registry did not directly quantify the prevalence of mental health concerns for individuals living with an ICD. However, the data does address the prevalence of complex conditions of diabetes, atrial fibrillation, and heart failure as factors associated with living with an ICD (Kremers et al., 2013).

Recipients of ICDs may express symptoms of fear, stress, and anxiety after implant, which arise from adjustment to the underlying condition and risk of SCA (Flanagan et al., 2010; Presciutti et al., 2019; Wilson et al., 2013). Moderate levels of anxiety (60%) and depression (40%) have occurred following ICD placement in response to adjustment to living with an ICD (Magyar-Russell et al., 2011; Presciutti et al., 2019; Schulz et al., 2013). One side effect of receiving an ICD has been the development of post-traumatic stress disorder (PTSD), due to the significant impact of receiving an ICD shock (Ladwig et al., 2008). A shock from an ICD is

designed to occur rapidly to provide life-saving therapies and is often painful (Sears et al., 2018). Recipients of ICDs have described the shock as feeling as though they have been kicked in the chest by a horse or as a sudden jolt to their body. Each time a shock is delivered, recipients of ICDs describe the event as being scary, and they worry they could have died. The presence of ICD shocks has been correlated with moderate levels of PTSD (Ladwig et al., 2008) and moderate to severe levels of anxiety (Magyar-Russell et al., 2011). Lasting psychological distress is present for up to 20% of individuals with an ICD, placing them at risk for destabilization (Ladwig et al., 2008; Magyar-Russell et al., 2011).

Anxiety and depression are often present in individuals with chronic cardiovascular disease or those who have experienced a myocardial infarction. There is some controversy as to whether the underlying cardiovascular condition places individuals at risk for mental illness; it is possible that having an underlying mental illness is exacerbated by the presence of the ICD. What is known is that the presence of ICD shocks can be disabling and undermine an individual's adjustment to an ICD (Magyar-Russell, et al., 2011; Sears, et al., 2018).

Significance

As the number of ICD implants continues to rise, identifying the factors that influence the well-being of individuals with an ICD has become important. Though the ICD is implanted to address physical health concerns, the health conditions requiring an ICD are quite severe and potentially stress inducing. Therefore, an individual receiving an ICD may require psychosocial support from their healthcare team to assist with the adjustment of living with the new technology (Doughtery et al., 2012; Kremers et al., 2013). Adaptation to living with an ICD is multifaceted in relation to individual responses centered on physiological, psychological, and social health (Dougherty et al., 2016; Dunbar et al., 2012). Although ICD technology continues

to evolve over time, there has been little change in the science related to living with an ICD. Historically, the focus on ICD care has been on the physical aspects and corresponding supportive strategies (Kuiper & Nyamtihi, 1991; Sears et al., 1999). Current strategies for living with an ICD continue to support compliance with clinical recommendations for adaptation to physiological changes and less on psychosocial needs (Dornelas & Sears, 2018; Ooi et al., 2016).

People with an ICD can be vulnerable due to potential progression of disease, risk for comorbidity and mortality, and potential costs of long-term management. A holistic approach to care that incorporates biopsychosocial health care delivery from an interdisciplinary team may improve individuals' experiences living with an ICD (Cuttita et al., 2014; Flanagan et al., 2010; Rozanski, 2016). A focus on solutions from both physical and psychosocial viewpoints may improve efficacy of care, reduce cost, and improve health outcomes (Rozanski, et al., 2005). Kuiper and Nyamtihi (1991) addressed the psychosocial impact of living with an ICD through exploration of stress perceptions and coping methods for living with an ICD. Similar results were noted after decades of changes to ICD technology, verifying the importance of continued review of psychosocial influences (Sears et al., 1999; Ford et al., 2013).

Influence of Trauma

Introduction to an ICD occurs during times of stress when individuals face life events that put them at risk for SCA and generate fears about mortality. The novel experience of living with an ICD may bring about a stressful response elicited by fear, hopelessness, or horror (Ford et al., 2013; Briere & Scott, 2015). Stressful or traumatic medical experiences that trigger emotional responses and override an individual's normal stabilizing resources meet the DSM-5 definition of a traumatic event (American Psychiatric Association [APA], 2013; Briere & Scott, 2015).

Psychological distress related to living with an ICD could manifest as clinical or subclinical symptoms of PTSD, anxiety, or depression (Ayers et al., 2009; Ladwig et al., 2008).

A critical component of a traumatic experience is perceived lack of control over circumstances (Carlson & Dalenberg, 2000). Feelings of lack of control may impact perceptions and adjustment to an ICD (Grew, 2017). Living with an ICD and the complexities of chronic cardiovascular conditions influence perceptions of control and can lead to chronic stress (Mundy & Baum, 2004). Initially, an anxiety response may be considered normal in circumstances where sense of control is threatened (APA, 2013; Briere & Scott, 2015). However, debilitating psychological distress may persist related to perceptions of threat to life, severity of condition, presence of stress, or socio-economic factors (Moye & Rouse, 2014; Mundy & Baum, 2004; Tulloch et al., 2014). Unchecked, psychological distress may potentially lead to maladjustment to an ICD. Disruption of psychosocial well-being could place individuals at risk for poor physical health, psychological distress, social dysfunction, and worsened outcomes (Ayers et al., 2009; Dunbar et al., 2012).

Having higher levels of psychosocial well-being plays a pivotal role in adjusting to a stressful experience. Responses to stressful events are dependent on influencing factors (Federal Interagency Forum on Aging-Related Statistics [FIFAS], 2016), including individual patient characteristics, mortality, presence of comorbidities, assessment of health, and psychological health. Individual perceptions of acceptance of an ICD are triggered by receiving a shock, altered life situation, or lack of support. Repetitive stressful conditions promote uncertainty which leads to psychosocial distress (Briere & Scott, 2015; Carlson & Dalenberg, 2000). Psychosocial distress is associated with dysfunctional adjustment to living with an ICD (Ayers et al., 2009; Humphreys et al., 2016). Dysfunctional adjustment exacerbates individual's reactions to pain or

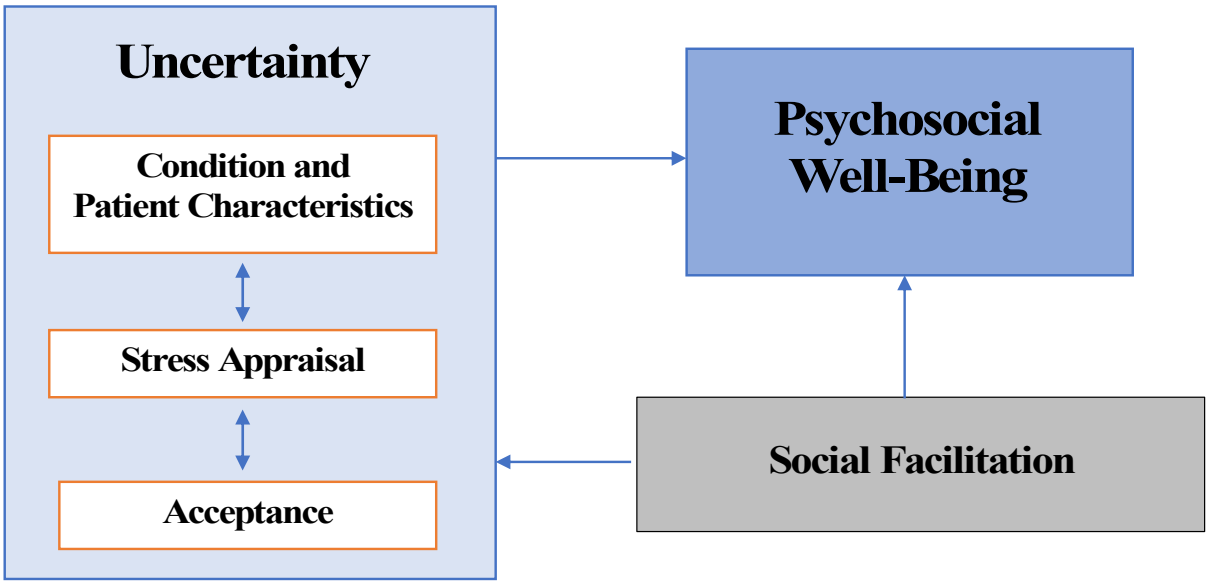
fear (Briere & Scott, 2015) and diminishes well-being. For older adult populations, psychosocial triggers often correlate with confidence in health status, which is buffered by the presence of social support (Tehee et al., 2019).

Conceptual Framework

Changes to lifestyle following ICD placement are potentially challenging for individuals, bringing uncertainty, and undermining a sense of normalcy (Flanagan et al., 2010; Flemme et al., 2011). A model was constructed to identify potential underlying factors related to uncertainty that may influence an individual's ability to adjust to their ICD implant, and maintain their psychosocial well-being (Figure 1).

Figure 1

The Impact of Uncertainty on Psychosocial Well-Being



Uncertainty

Uncertainty is likely to occur for individuals when reminded of their mortality. Individuals adjusting to life with an ICD balance the dread of shocks and risk for SCA. When

fearing SCA, individuals living with an ICD often view the device as a lifeline to survival (Manuel & Brunger, 2016).

The ability to adjust to life with an ICD depends on uncertainty-related characteristics, including condition, stress appraisal, and acceptance of an ICD, which are associated with an individual's social facilitation and psychosocial well-being experiences.

Condition and Patient Characteristics

Uncertainty due to the complexity and unpredictability of treatment, such as an ICD, can undermine an individual's ability to adjust to living with an ICD (Clayton et al., 2018). Identifying comorbidities, knowledge, and changes in life patterns that exacerbate uncertainty and adjustment to an ICD are essential to well-being. Assuming control over life circumstances and conditions enables individuals to manage their fear and uncertainty when living with an ICD (Grey et al., 2015).

Stress Appraisal

Stress for individuals with chronic conditions emerges from the constant threat of a diminishing health status, which may cause uncertainty (Lazarus, 1974). The uncertainty can decrease their psychosocial well-being when there is a continuation or reoccurrence of the threat to an individual's health, such as living with an ICD (Clayton et al., 2018). Individuals who are adjusting to living with an ICD may report decreased stress appraisal and thus their uncertainty, promoting their psychosocial well-being.

Acceptance

Acceptance of life with an ICD involves adjusting to the presence of the technology, along with the potential risks. Ongoing acceptance of an ICD enables individuals to experience a progressive return to daily activities and restructuring of their new life (Sears et al., 2013). As

individuals adjust to living with the ICD, they decrease uncertainty and progress toward sustained psychosocial well-being (Grey et al., 2015).

Social Facilitation

The impact of individuals living with a stressor, such as an ICD, can be positive or negative, depending on their relationships within their social networks (Clayton et al., 2018; Grey et al., 2015; Segrin & Taylor, 2007). Two main reactions to the presence of a social network are identified in social facilitation literature: a negative, fearful response or a positive, self-confident response (Uziel, 2007). Individuals who activate their social resources to adjust positively to living with the ICD decrease their uncertainty while increasing their ability to move toward psychosocial well-being (Clayton et al., 2018; Grey et al., 2015; Uziel, 2007).

Psychosocial Well-Being

Measurements of well-being, health-related quality of life (HRQoL), and participation within the environment address how well an individual is adjusting to a chronic condition (DHHS, 2020). For individuals living with an ICD, well-being can be measured by assessing the individual's return to biopsychosocial functioning, participation in activities, and socialization. Well-being for an individual with an ICD requires that they shift, cognitively and emotionally, to an optimistic outlook of the ICD (Habibović et al., 2018; Sears et al., 2004). The rate and strength of an individual's adjustment to living with an ICD are influenced by their underlying condition, stress experienced, and acceptance of the technology (Sears et al., 2013). Individuals who experience higher rates of adjustment to life changes have reported higher rates of well-being (DHHS, 2020). Additionally, having access to a positive support network of people, such as a spouse or relative, helps decrease an individual's uncertainty, contributing to psychosocial well-being. As individuals explore their new way of living, they can start taking personal control

of their life, further improving their adjustment to living with an ICD (Clayton et al., 2018; Grey et al., 2015).

Supporting Rationale

Health is a socially based construct in which interactions with the environment, society, and social support networks determine an individual's perception of health and hope for their future (Stevens, 2018). Currently, science supports a shift in the model of care to support individual patient experiences to manage the ICD (Dunbar et al., 2012; Ford et al., 2013) as evidenced by the advent of shared decision-making for adults with an ICD (American College of Cardiology [ACC], 2019). An objective view of the complexities, and psychosocial and environmental factors, experienced by adults with ICDs provides a foundation for adjusting to an ICD (Dunbar et al., 2012).

Positive well-being is associated with adults experiencing improved cardiovascular health, including decreased morbidity and mortality rates (Centers for Disease Control and Prevention [CDC], 2020). Psychological and social factors may impact an individual's ability to adjust to living with an ICD and improve psychosocial well-being, including emotional response, cognitive appraisal, and social support (Dornelas & Sears, 2018). Social support may buffer reactions to stressful life events (Zimet et al., 1988), influencing an individual's perceptions of stress and well-being. Adjusting to living with an ICD may be directly related to patient characteristics identified by social determinants of health (SDOH), perception of health status, and health behaviors of aged individuals (FIFAS, 2016). Self-reported needs assessments identify individual concerns about living with an ICD as a basis for formulating interventions.

Statement of the Problem

Individuals are often uncertain about life with an ICD to treat their potentially life-threatening arrhythmias. Healthcare professionals' discomfort with discussing sensitive topics such as mortality or end-of-life decisions exacerbates individuals' uncertainty and their ability to make decisions concerning their ICD (Fumagalli et al., 2018). However, healthcare providers who can discuss sensitive topics with individuals requiring an ICD enable identifying strategies to decrease uncertainty and thus improve social facilitation and psychosocial well-being while living with an ICD. Living with an ICD may be impacted by an individual's: Condition, Stress Appraisal, Acceptance, and Social Facilitation. A conceptual model *Impact of Uncertainty on Psychosocial Well-Being* (Figure 1) demonstrates the interaction between uncertainty variables, including condition, stress appraisal, and acceptance with social facilitation and psychosocial well-being. Psychosocial well-being improves when the levels of uncertainty decrease, and social facilitation is enhanced.

Purpose and Specific Aims

The purpose of this study is to examine how an individuals' perceptions of living with an ICD impacts their psychosocial well-being. Primary aims of this study are to examine the associations between knowledge, severity of cardiovascular condition, individual stress appraisal, acceptance of ICD, and social facilitation with psychosocial well-being among adults with an ICD.

Research Questions

1. What is the cardiovascular condition for necessitating an ICD and knowledge level of an ICD among adults living with an ICD?
2. What is the individual stress appraisal among adults with an ICD?

3. What is the acceptance level of an ICD among adults with an ICD?

4. What is the level of social facilitation among adults with an ICD?

5. What is the level of psychosocial well-being among adults with an ICD?

6. Controlling for age and sex, do knowledge of the ICD, severity of cardiovascular condition, individual stress appraisal, acceptance of ICD, and social facilitation predict psychosocial well-being among adults with an ICD?

Definition of Terms

The terms within the model *The Impact of Uncertainty on Psychosocial Well-Being,* are conceptualized for this study to examine how individuals' perceptions of living with an ICD impact their psychosocial well-being.

Uncertainty

Uncertainty in adjustment to living with an ICD will by conceptualized using the terms *condition and patient characteristics*, *stress appraisal*, and *acceptance*. These concepts are operationalized utilizing responses to items within patient characteristics questionnaire and the Florida Patient Acceptance Scale (FPAS) to understand the ways in which aspects of uncertainty influence living with an ICD.

Condition and Patient Characteristics

Conceptual. Identifying influencing factors such as SDOH, lifestyle, and ICD therapies provide information on individual foundational differences. Condition and patient characteristics conceptually measure the demographics, life changes, and perception of severity of the condition that influences an individual's ability to adjust to an ICD.

Operational. Reponses to the patient characteristics form will operationalize condition and patient characteristics. The reported items related to diagnosis, comorbidities, criteria for

ICD implant, and presence of shocks determine the severity of condition. Responses to knowledge of the ICD questions from the FPAS will also operationalize condition and provide information on the individual's understanding of their ICD.

Stress Appraisal

Conceptual. Stress appraisal is conceptualized by assessing emotional stability and reactions to the demands to change lifestyle after a life event. Perceptions of stress can interfere with enjoying and engaging in life after an ICD.

Operational. Responses to the FPAS will operationalize appraisal of stress.

Acceptance

Conceptual. Acceptance is conceptualized by adjustment to living with the ICD as evidenced by returning to physical and psychosocial activities and interactions. Adjustment to living with an ICD can be impacted by threat perceptions identified through cognitive and emotional representations assigned to various aspects of living with an ICD. Conceptualizing the ICD experience through these representations identifies feelings of control and emotional response to the ICD (Leventhal et al., 2020).

Operational. Acceptance will be operationally defined from responses to the FPAS.

Social Facilitation

Conceptual

Social Facilitation is conceptualized as the presence and influence of support, and the degree of collaboration with supportive networks to promote change.

Operational

Social facilitation will be operationalized by responses to the Multidimensional Scale of Perceived Social Support (MSPSS).

Psychosocial Well-Being

Conceptual

Well-being is a subjective construct conceptually defined through identification of interactions between social, psychological, and health-related dimensions (Wright et al., 2009). Therefore, well-being will be conceptualized by addressing the psychosocial aspects of living well with an ICD.

Operational

Defined by responses to the Psychological Well-being Scale (PWB).

Descriptions of Manuscripts

Three manuscripts will emerge from this investigation. The first manuscript within Chapter Two will systematically review living with an ICD. This manuscript will focus on the nature of the science addressing the psychosocial aspects of living with an ICD. The systematic review provides a foundation for the conceptual framework of this study by providing an overview of psychosocial constructs that influence living with an ICD. The manuscript's focus will be identifying the potential factors influencing the psychosocial well-being of adults living with an ICD. A contextualized description of variables influencing psychosocial well-being may provide valuable information on living with an ICD. The second manuscript in Chapter Two will focus on understanding the concept of social facilitation and the potential relationship with adults' adjustment to living with an ICD. Adults living with an ICD have various social networks. A concept analysis of how those networks interact socially may provide insight into their influences on uncertainty and individual psychosocial well-being. The third manuscript will incorporate the findings reported in Chapter Four. The manuscript on the findings will provide an overview of the associations between uncertainty, social facilitation, and psychosocial well-

being for individuals living with an ICD. The plan will be for each manuscript to provide a valuable component to the next, allowing for a rigorous examination of the psychosocial well-being of adults living with an ICD.

Chapter Summary

The importance of addressing the psychosocial factors potentially impacting psychosocial well-being for adults living with an ICD was addressed in this chapter. A model was developed to provide a framework to view the impact uncertainty on psychosocial well-being for adults living with an ICD and the role of social facilitation. Addressing the potential impact of these factors on psychosocial well-being can provide important information for guiding individuals in their adjustment to living with an ICD.

Chapter Two: State of the Science

Chapter two includes three parts: (A) State of the Science, (B) Manuscript One, and (C) Manuscript Two. Each section will provide background to inform this study on the state of the science related to implantable cardioverter defibrillators (ICD). The state of the science provides an overview of ICD criteria, procedures, and management. Manuscript One will review the psychosocial factors that influence living with an ICD. The manuscript focuses on the influencing factors related to living with an ICD that may impact psychosocial well-being. Manuscript Two analyzes the concept of social facilitation concerning living with an ICD. The manuscript provides information on how potential support networks influence uncertainty and psychosocial well-being from the presence, influence, and collaboration standpoint.

Part A: An Overview of the State of the Science

Part A includes an overview of the science of living with an ICD, including what an ICD is and does, why individuals receive an ICD, and follow up and concerns after implant. This section also discusses the gaps in the literature and the conceptualization of the variables utilized in this study.

What is an ICD?

An ICD is a mechanical device indicated to improve survival from a sudden cardiac arrest (SCA). By delivering therapy quickly, in the form of anti-tachycardia pacing or a shock, deterioration to sudden cardiac death (SCD) can be avoided (Ziles et al., 2006). The complexities of adjusting to living with an ICD are related to the device, delivered therapy, arrythmias, criteria for implant, procedures, and follow up. Each of these may have an impact on the way individuals respond to the device and alter their ways of living (Ladwig et al., 2008).

The Body of the ICD

An ICD system is comprised of a generator and leads. The ICD generator, the size of a small deck of cards, houses the electronic components of the ICD system. Electrical components within the generator include a lithium battery, electronic components to deliver therapies, and programable software. The average life of an ICD battery is 5 to 7 years, with earlier degradation of the battery life possible through frequent therapies from shocks. A capacitor system within the generator stores a charge that can deliver up to 35 joules of electricity in the form of a shock. The leads deliver therapy from the generator through pacing and detection electrodes and shocking coils. The placement of the generator and leads within the body are designed for optimal deliverance of therapy across a vector traversing the heart. The optimum vector recognized for successful shocks places the generator under the left clavicle and leads through left subclavian vein to the heart. Right-sided generator placement and access through the right subclavian vein is reserved for those individuals with an occluded left subclavian or history of infection of a left-sided placement (Braunschweig et al., 2010; Libby et al., 2021).

ICD Deliverable Therapies

In addition to pacing for bradycardia like a pacemaker, an ICD detects the presence of life-threatening arrhythmias and implements therapeutic shocks. Ventricular tachycardia (VT) and ventricular fibrillation (VF) are treatable arrhythmias the ICD is designed to shock (Philippon et al., 2017). When specified detection criteria are met, the device follows a programmed algorithm to initiate anti-tachycardia pacing or deliver a shock in under 30 seconds (Madhavan & Friedman, 2013). A predetermined optimal energy delivery resets the heart to a normal rhythm within a tested defibrillation threshold. Delivered therapeutic shocks are logged within the generator and retrieved via manual interrogation using a programmer or remote access

through a home monitor (Philippon et al., 2017). The ICD will follow the programmed algorithms to treat suspected VT or VF in a continuous cycle of detection and shock until the programmed criteria are no longer met. Because of this, individuals may receive one or more shocks. Multiple shocks from the ICD are called electrical, or shock storms and are a medical emergency. Individuals having an appropriate shock need evaluation for medication changes, re-programming, or surgery. Inappropriate shocks occur when the ICD has delivered a shock for non-life-threatening arrhythmias due to programming, device, or lead malfunction. The programable criteria for an ICD include discriminating software for atrial versus ventricular arrhythmia and heart rate cut-offs to limit the chance of inappropriate shocks. Issues addressed with re-programming the ICD include discrimination of slow VT, atrial arrhythmia with aberrancy, and setting up stacked therapies with anti-tachycardia pacing prior to the shock. Shocks due to a fractured wire or device recall require immediate notification to provide a safe plan for intervention (Madhavan & Friedman, 2013; Philippon et al., 2017). Individuals may report false positive phantom shocks or feel as though they had a shock not confirmed by device interrogation. False negative shocks occur when an individual is unaware an arrhythmia or a shock has occurred, but the shocks are confirmed on device interrogation (Philippon et al., 2017).

Meeting Criteria for ICD Implant

The heterogenetic nature of the underlying conditions together with SCA risk provide a foundation of the complexity related to managing individuals with an ICD (Al-Khatib et al., 2017; Santini et al., 2007). Primary prevention ACC/AHA guideline criteria for ICD therapy are based on studies showing efficacy in reduction of SCA and mortality. Secondary prevention criteria for ICD therapy are recommended for those who have survived an SCA or have sustained ventricular tachycardia (VT) from a non-reversible cause (Al-Khatib et al., 2017). The

pathophysiology and criteria for implant of an ICD qualify the therapy as a potential stressful or traumatic medical experience per DSM-5 criteria, especially in relation to shocks (Briere & Scott, 2015).

Complexity of Underlying Condition

A complex ICD decision matrix includes evaluation of (a) implant criteria, (b) underlying diagnoses, and (c) risk for potential SCA (Al-Khatib et al., 2017). The complexities of the underlying conditions partnered with SCA risk are listed in Table 2.1. Factors related to the variety of conditions associated with criteria for ICD placement can influence individual perceptions of the ICD. Individual adjustment to living with an ICD can vary based on complexity of underlying conditions and therapies delivered. Psychosocial factors influencing a decision for ICD are not formally included within the criteria (AHA, 2019; Al-Khatib et al., 2017; Santini et al., 2007). Other reasons for complexity of implant decisions include the presence of atrial fibrillation or heart failure. The surgeon may choose an ICD that has programmability to allow for discrimination of atrial tachycardias from ventricular tachycardias to avoid inappropriate shocks. Individuals with complex comorbidity, such as heart failure, may benefit from a left ventricular pacing wire to allow for bi-ventricular pacing and resynchronization of the heart. Devices that provide cardiac resynchronization therapy (CRT) are designated CRT-P for pacemakers or CRT-D for defibrillators (Braunschweig et al., 2010).

Table 2.1

Cardiovascular Conditions with Risk of SCA for ICD Implant

CAUSES	CONDITION	RISK FACTORS
Ischemic	Coronary artery disease (CAD) Myocardial infarction (MI) Cardiomyopathy	Location of MI Presence of wall motion abnormalities or scarring. Presence VT or VF, Low ejection fraction (EF) <30%, Waiting period 40 days after MI
Stress	Tako-subo, Post-Partum	Normal recovery over time
Genetic: Structural Arrhythmia Cardiomyopathy	Idiopathic dilated cardiomyopathy Hypertrophic cardiomyopathy (HCM)	Family history of SCD Syncope Presence VT or VF Low EF <35%
Heart wall or muscle changes	HCM Sarcoidosis Arrhythmogenic right ventricular dysplasia (ARVD)	Genetic or non-genetic Family history Syncope and/or hypotension with exercise Presence VT or VF Enlargement, dilation, or infiltration
Ion channels Disorders	Brugada syndrome Catecholaminergic induced VT Long QT syndrome	Genetic Family history of SCD Syncope Presence of VT/VF or induced with testing
Syncope	Unexplained syncope	Presence of VT/VF or induced with testing
Arrythmia	VT or VF	Presence of VT/VF or induced with testing
Other	Drug or Alcohol abuse Uncontrolled hypertension Uncontrolled tachycardia	Low EF < 35% Syncope Arrhythmia

Note: Adapted from *"2*017 AHA/ACC/HRS Guideline for Management of Patients With Ventricular Arrhythmias and the Prevention of Sudden Cardiac Death: Executive Summary: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines and the Heart Rhythm Society." by Al-Khatib, S., Stevenson, W., Ackerman, M., Bryant, W., Callans, D., Curtis, A., ... Page, R. , 2018. Copyright 2018 by *Circulation.*

Primary Versus Secondary Prevention

Primary prevention ACC/AHA guideline criteria for an ICD are based on studies showing efficacy in reduction of SCA and mortality. Individuals with SCA risk with their underlying cardiac condition or have inducible VT or VF meet primary prevention criteria. This group has not had exposure to SCA or the implications to mortality (Bansch et al., 2002; Al-Khatib, et al., 2017). Secondary prevention criteria include individuals who have an episode of sustained VT from a non-reversible cause or survived SCA. These individuals have experienced the suddenness of a life-threatening situation and lived through the event (Borne et al., 2017 Al-Khatib et al., 2017). Supporting studies for the criteria are outlined in Table 2.2.

ICD Procedures

General procedures, which are similar in pre-, peri-, and post-operative steps to receiving a pacemaker, include initial implant and generator replacement. Generator replacement occurs after the elective replacement indication (ERI) has alerted and before end of life (EOL) of the battery (Braunschweig et al., 2010). The difference in procedure for an ICD is the defibrillation testing (DFT) that occurs after the implant to test accuracy and efficiency of shocks. DFT occurs by placing the individual in a life-threatening rhythm and testing the effectiveness of the ICD in delivering shocks. The patient is of course sedated during the DFT testing in the catheterization lab and safety precautions for external defibrillation are in place. Other procedures that may add to the psychological impact of having an ICD are correction procedures for lead dislodgement, device or lead malfunction, infection, and extraction (Philippon et al., 2017).

Table 2.2

ICD Implant Criteria and Studies on Efficacy of Therapy

RECOMMENDATON	STUDY	CRITERIA
Primary Prevention: Class I recommendation (level of evidence B)	MADIT I	Non-sustained Ventricular Tachycardia (VT) on Holter monitoring and inducible, non-suppressible VT or Ventricular Fibrillation (VF) at electrophysiologic study
Class IIA recommendation (level of evidence B)	MADIT II	Left Ventricular Ejection Fraction (LVEF) <30%
	SCD-HEFT	Ischemic or non-ischemic heart disease, LVEF <35%, Presence of heart failure
	COMPANION	Combined Cardiac Resynchronization, Therapy (CRT) and ICD therapy, Ischemic and non-ischemic advanced heart failure, LVEF <35%, Presence of intraventricular conduction delay (IVCD)
Secondary Prevention: Class I recommendation (evidence level A)	AVID CASH	Patients surviving cardiac arrest caused by VT or VF, Sustained hemodynamically stable VT not due to transient or reversible causes with or without syncope

Note: Adapted from *"2*017 AHA/ACC/HRS Guideline for Management of Patients With Ventricular Arrhythmias and the Prevention of Sudden Cardiac Death: Executive Summary: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines and the Heart Rhythm Society." by Al-Khatib, S., Stevenson, W., Ackerman, M., Bryant, W., Callans, D., Curtis, A., ... Page, R. , 2018. Copyright 2018 by *Circulation* and *"*Meta-analysis of the implantable cardioverter defibrillator secondary prevention trials. AVID, CASH and CIDS studies. Antiarrhythmics vs Implantable Defibrillator study. Cardiac Arrest Study Hamburg. Canadian Implantable Defibrillator Study" by Connolly S.J., Hallstrom A.P., Cappato R., Schron E.B., Kuck K.H., Zipes D.P., Greene H.L., Boczor S., Domanski M., Follmann D., Gent M., Roberts R.S., 2000. Copy right 2000 by *European Heart Journal.* In public domain.

Centers for Implant and Follow Up

Healthcare centers that have adequate personnel and equipment for the management of ICD therapy are more often located in major metropolitan areas. Larger centers often have required specialized heart catheterization labs with operating room back-up for cardiovascular emergencies, defibrillation testing, or potential complications. Specially trained cardiologists or electrophysiologists surgically implant and manage ICD therapy for individuals. Specialized nurses and technicians are trained to interrogate the ICD to download stored data, including shocks and arrythmias. Routine follow up is provided in person by a specially trained device nurse at weeks 1 and 6 post-implant to ensure proper healing of the implant site and lead stability. After the initial follow up, individuals are scheduled for remote checks every three months and an annual check and visit with a provider. Individuals that receive a shock or treatments are scheduled more often on an as needed basis. Complications such as device recall, infection, or device failure require care at the major centers (Braunschweig et al., 2010).

Close monitoring may be a combination of in-person and remote monitoring through electronic ICD interrogation. Both remote and in-person visits can provide information on battery life, shocks, stored rhythms and interpretation of therapies. However, assessment of the leads and reprogramming of the device or therapies requires an in-person visit. Annual in-person visits for routine full-device interrogation are completed by trained registered nurses or device nurses. Individuals are scheduled once yearly at a device center of a major hospital system or their rural satellite campuses where nurses are present. Remote device interrogation is completed every 3 to 6 months through a remote telephonic system provided to individuals from the device company. Individuals with an ICD are trained on its use and can expect a call from the device nurse 24 to 48 hours after sending a transmission. It is not necessary for individuals with an ICD

to relocate from rural areas to be near major health centers for routine care. It may be necessary to travel longer distances to larger centers when complex care is required. Individuals that live in rural areas may go to the nearest emergency room for stabilization and transfer for treatment to larger centers as needed. Emergency room physicians and staff are trained in stabilizing individuals presenting with shocks or complications with an ICD. Individuals who travel within the United States for prolonged vacations or to winter homes can choose to bring their remote system with them to continue appointments. Individuals with an ICD who travel for prolonged times would need to establish care with providers in the area if case their health requires in-person care or device interrogations (Braunschweig et al., 2010).

Driving Restrictions

Driving restrictions for individuals who receive an ICD of primary prevention are for 1-week post-procedure. For the safety of the individual and the public, longer driving restrictions are recommended for individuals with life-threatening arrhythmias that may lead to syncope, loss of consciousness, or delivery of a shock. Depending on state legislation, adults with an ICD implanted due to secondary prevention have a standard driving restriction of 3 or 6 months. Resumption of driving privileges occurs when the individual has no arrhythmias or shocks from the ICD confirmed by self-reporting and interrogating the device (Braunschweig et al., 2010; Epstein et al., 2007). Interstate commercial driving licenses are restricted long-term for anyone with an ICD due to ongoing safety risks. Each state may have different regulations for commercial driving within the state (U.S. Department of Transportation [DOT], 2015).

Influence of Personality

Type A personality has been found to exacerbate coronary artery disease due to the nature of these individuals being driven and prone to stress. Type B personalities tend to have

more laid-back personality traits. A Type D personality is an individual who is inhibited and uncomfortable in social situations, has difficulty making friends, and tends to experience feelings of anger, anxiety, depression, and discontent with others. Individuals with an ICD who have a Type D personality are at risk for psychosocial dysfunction and potential barrier to adjustment (Berrios et al., 2017; Clark, 2021). In several studies, ICD recipients with a Type D personality correlated with psychological health deterioration and worsening of HRQoL over time (Israelsson et al., 2018; Pederson et al., 2013; Pederson et al., 2017).

Review of Gaps in the Literature

Rural Living and Sites of Care

Individuals from rural areas often travel over an hour for specialized care related to their ICD. Examples of care provided at larger centers include (a) device procedures, (b) urgent arrhythmia management, and (c) treatment for device complications. Individuals who travel for care identify barriers to accessing support from family or friends while receiving care away from home. Individuals with an ICD have also expressed concerns related to the lack of knowledgeable and personalized care in rural settings due to (a) reliance on technology for remote follow up, (b) fear of delayed care due to distance to large centers, and (c) and disconnect in the continuity of care when treated by local providers and hospitals (Magnusson et al., 2017). Identifying the needs of rural populations needs further study for individuals living with an ICD to address interventions that could alleviate the concerns.

Providing Knowledge on Psychosocial Factors

Clinical supportive strategies for recipients of an ICD have focused on providing knowledge of ICD therapy and improving physiological adjustment after implant (Dornelas & Sears, 2018) and less on the psychosocial impact of having an ICD (Dunbar et al., 2012). A

holistic approach to care for this population is necessary to understand the psychosocial impact on adjustment and daily life (Flannigan et al., 2010). Research is needed on interventions to reduce stress, increase activity, and improve the social interactions for individuals living with an ICD to impact their psychosocial well-being and HRQoL (Hammash et al., 2019).

Healthy of relationships and interactions with family and friends can influence an individual's adjustment to living with an ICD (Dougherty et al., 2016). Analyzing the support networks of individuals adjusting to advanced heart disease and an ICD may identify how emotional and physical intimacy reduces uncertainty and stress (Dornelas & Sears, 2018; Dougherty et al., 2019). Future research should focus on strengthening spousal support and improving a patient's knowledge about living with an ICD to improve the psychosocial well-being of the family unit.

Interdisciplinary Teams and Organizational Structure

The influence of organizational policies and procedures on psychosocial adjustment to living with an ICD is understudied. Bolse et al. (2013) identified gaps in the literature related to how algorithms designed by organizational structures influence routine ICD care guidelines. A lack of coordination between behavioral health and cardiology specialty care provides costly, inefficient care and poor health outcomes for individuals with an ICD (Sears et al., 2013). Further research is needed to identify the role of interdisciplinary teams with tailored strategies to reduce the risk of psychosocial distress and improve ICD adjustment and well-being. Research should also address the roles of specialized team members along the health continuum of individuals living with an ICD.

End-of-Life Concerns

Healthcare professionals often do not address the psychosocial and end-of-life concerns of individuals living with an ICD due to a lack of training or comfort. Consistent with this, depression and anxiety are also often overlooked at end of life. In several multinational studies, researchers reported that end-of-life issues rarely were discussed with individuals who received any device independent of age. Of the respondents, 70% to 84% had not discussed end of life with their physician before receiving the ICD. Limited discussions occur on when shock therapy can be deactivated as a disease progresses or a terminal illness ensues (Fumagalli et al., 2018; Haugaa et al., 2018). Studies also show that spouses of ICD recipients seldom had discussions with healthcare professionals about end of life and the ICD. Lack of information and end-of-life planning increases distress at end of life and the risk of a stressful death experience for individuals and their social network (Fluur et al., 2013; Haugaa et al., 2018; Ooi et al., 2018; Pederson et al., 2016). Future research on living with an ICD should include studies to address processes to promote palliative care referrals in this population to address end-of-life concerns.

Conceptual Background of Variables

An ICD prolongs life when there is a risk for SCA, but balancing the risk for SCA, the pain and fear of shocks, and the desire to avoid death may bring uncertainty into daily living with the ICD. Although individuals have agreed to this life-saving treatment, the psychosocial complexities of living with an ICD and the underlying chronic cardiovascular condition may impact well-being. Variables chosen for this study identify factors of uncertainty such as condition and patient characteristics, stress appraisal, acceptance of the technology, and the presence of social facilitation that may influence the individual's psychosocial well-being. The

measurement instruments chosen to measure the variables complemented the underlying philosophy of the conceptual model used.

Views of Living with an ICD

Healthcare personnel and ICD recipients may have different perspectives on how to define a "good life" when living with an ICD. Individuals who receive an ICD often hope the device is a cure that continues their former lives without interference from disease or treatment. In contrast, health professionals view the ICD as a means of reducing mortality that allows for adjustment of the individual's life patterns to improve care management. The dichotomy of these expectations for living a good life may influence the ability of individuals to understand the role of an ICD in their treatment and the necessary psychosocial adjustments needed to incorporate the ICD into their life (Grew, 2017). Identifying factors of uncertainty due to condition and patient characteristics, stress appraisal, and acceptance of the technology is essential to adjust perceptions and improve psychosocial well-being for those living with an ICD.

Uncertainty of Living with an ICD

Holistic care for individuals with an ICD provides a balanced focus on the biopsychosocial needs of an individual (Dunbar et al., 2005). Each independent variable was measured to assess associations with psychosocial well-being. Uncertainty was measured by *condition, stress appraisal, and acceptance*.

Condition

The severity of the underlying condition and individual patient characteristics impact the level of psychological distress in living with an ICD (Isrealson et al., 2018; Magnusson et al., 2017; Wilson et al., 2013). Conceptually, condition impacts the risk level of SCA and psychosocial well-being. The complexities of the underlying condition can lead to feelings of

uncertainty as individuals contemplate the potential for shocks or death (Mauro, 2010). Individuals appraise their condition by assigning cognitive and emotional representations to their experiences, feelings of control, and emotional responses to their condition. The condition's representations worsen with low comprehension, the severity of the condition, and limitations to lifestyle. If left unchecked, a cycle propagates a sense of loss of control over the condition, bringing fear and potentially undermining adjustment to living with the ICD (Leventhal et al., 2021). Lack of control or knowledge of the condition is related to the uncertainty of living with an ICD (Dehghanzadeh et al., 2018).

Stress Appraisal

Stress appraisal, conceptually defined, measures emotional stability and demands to change lifestyle in reaction to a life event. Perception of stress is directly related to feelings of unpredictability, loss of control, and feeling overwhelmed (Cohen et al., 1983). Perceived threats often correlate with emotional responses to a stressor such as fear, anger, or helplessness (Briere & Scott, 2015). The experience with a stressful life event, such as having an ICD, is related to how the individual appraises the life event in relation to their overall ability and resources to adjust (Lazarus, 1984). Appraisal of stress may have general influence on all areas of well-being.

Acceptance

Due to the personal nature of implanted technology, acceptance of ICD technology and attitude toward device therapy may impact a sense of well-being related to living with an ICD (Flemme et al., 2011). Psychological factors affecting acceptance and adjustment to an ICD can be identified through screening for a return to activities and lifestyle (Versteeg et al., 2012). Seeing the ICD with an optimistic attitude has been found to increase the likelihood of accepting

the device as a part of a new life. Individual positive adjustments to the ICD promote actions that lead to the outcome of living with the ICD (Hale et al., 2007).

Social Facilitation

Assessment of social facilitation identifies the level of supportive networks available to an individual to promote change (Ryan & Sawin, 2009). Social facilitation is conceptualized as the influence the presence of others and degree of collaboration have on individual experiences of those living with an ICD. For some circumstances, social networks that are supportive have been found to act as a buffer for reactions to stressful life events (Zimet et al, 1988). For others, individual performance may be personal and, depending on the nature of the support, the social network can have a negative or positive effect (Briere & Scott, 2015). In general, individuals with a strong and active social support network are 50% more likely to have improved health and mortality than those who do not (Holt-Lunstad et al., 2010). These finding stresses the importance of addressing the potentially varied impact of social facilitation on psychosocial well-being for those living with an ICD.

Psychosocial Well-Being

Well-being can be measured from multiple perspectives: (a) hedonic, (b) eudemonic, or (c) social. Diener's hedonic model of subjective well-being is based on emotional positivity and satisfaction with life (Diener et al., 1999). In contrast, Ryff's (1989) psychological, eudemonic model addresses well-being from a goal perspective in reaching full function and individual meaning of life. Keye's (1998) social model addresses social well-being in five dimensions. Attempts are underway to develop a model that incorporates all three perspectives of well-being, but they have yet to be perfected and tested in varied populations. Therefore, for this study, well-being is addressed from the eudemonic view of goals, to living well from a psychosocial

perspective that considers the perception of health, environment, and support networks necessary to living with an ICD.

Ryff's (1989) definition of well-being is based on Aristotle's Nichomachean ethics. The core philosophical meaning of a good life, defined by Aristotle, is living well by having a life that is balanced, whole, and honorable. The Psychological Well-Being model includes six psychological domains: (a) autonomy, (b) self-acceptance, (c) environmental mastery, (d) purpose in life, (e) personal growth, and (f) positive relations with others (Ryff & Keyes, 1995; Ryff & Singer, 2008). The domains are based on a eudemonic approach to well-being focused on life fulfillment, functioning, and realization (Cooke et. al., 2016). Every domain further addresses separate portions of well-being that are central to that focus. The domain autonomy addresses whether an individual has developed personal standards they use to regulate their own behavior independently or if they are swayed by outside influences. The self-acceptance domain focuses on an individual's positive attitude toward themselves and their life that may impact how they view their world and their roles. Individuals who have mastery over their lives live a life of competence in which they seek out opportunities and create avenues to meet their personal needs. Those individuals with a purpose in life utilize self-directed goal setting that aligns with their beliefs to create purpose. The domain of personal growth addresses the need for continued development of self and engagement in new experiences to promote continued self-improvement over time. And lastly, the domain positive relations with others measures an individual's ability to build strong relationships and have empathy for others. (Ryff & Keyes, 1995; Ryff & Singer, 2008). The meanings of high and low scores on the Psychological Well-Being Scale are listed in Table 2.3.

Table 2.3

Meaning of Scores in the Psychological Well-Being (PWB) Scale

Subscale	High Scores	Low Scores
Autonomy	Self-determined, independent, sets personal standards, regulates own behavior, resists social pressures	Concerned about others' expectations, relies on others to make decisions, conforms socially
Environmental Mastery	Managing environment well, control over multiple complex external activities, effectively uses opportunities, aligns to personal goals and values	Difficulty managing daily affairs, feels unable to change environment, feels lack of control, unaware of opportunities
Personal Growth	Continued development, aware of self and grows and expands views, open to new experiences, aware of self-improvement, changes reflect self-knowledge and effectiveness	Personal stagnation, lacks sense of improvement or expansion over time, bored or uninterested in life, unable to develop new attitudes or behaviors
Positive relation with Others	Warm and trusting relationships; concerned about others, strong empathy, affection, and intimacy; understands give and take	Few close, trusting relationships; difficulty with others; isolated and frustrated in relationships; not willing to make compromises
Purpose in Life	Has goals in life, sense of direction, feels meaning of life, holds beliefs that give life purpose, has aims and objectives for living	Lacks meaning in life, few goals or aims, lacks direction, does not see purpose in past life, no outlooks or beliefs that give life meaning
Self-Acceptance	Positive attitude; acknowledges and accepts self, including good and bad qualities; feels positive of past life	Dissatisfied with self, disappointed with past life, troubled about personal qualities and what is

Note: Used With permission. (Ryff, 1989; Ryff & Keyes, 1995; Ryff & Singer, 2008).

Part B: Manuscript One

Systematic Review Identifying Psychosocial Factors Impacting Living with an ICD

ABSTRACT

Aims: Explore psychosocial factors that influence living with an ICD through a trauma-informed lens.

Design: Systematic review.

Data sources: Search of electronic databases including CINAHL, PubMed, and PsycINFO, Google Scholar using the keywords, yielded 26 eligible articles published from 12/2009 to 12/2020.

Review Methods: A systematic review of the articles following PRISMA guidelines, with quality analysis using the Johns Hopkins Nursing Evidence-Based Practice model.

Results: Factors were categorized under condition, stress appraisal, acceptance, social facilitation, and potential impact on well-being. Factors identified included (a) seeking knowledge, (b) condition, (c) psychological concerns, (d) living with uncertainty, (e) fear of ICD shocks (f) support networks, and (g) a new way of living.

Conclusion: Interdisciplinary teams need to provide encouragement and support to individuals with an implantable cardioverter defibrillator to address uncertainty and improve psychosocial well-being.

Key words: implantable cardioverter defibrillator, coping or adaptation, living with ICD

In the United States, nearly 310,000 deaths occur annually from sudden cardiac arrest (SCA) (NMA, 2008). Cardiac conditions and a history of ventricular arrhythmias can lead to SCA, a life-threatening medical emergency that places individuals at risk for dying. The surgical insertion of an implantable cardioverter-defibrillator (ICD) is the standard treatment for individuals at risk for SCA. Therapy from an ICD includes detection of life-threatening arrhythmias and treatment with an electrical shock to the heart. Whenever an individual experiences a life-threatening arrhythmia, an ICD provides a jolt to return the heart to a normal or non-life-threatening rhythm. The jolt from the ICD, also termed a shock, is sudden and painful, like an unexpected kick to the chest with significant force (Sears et al., 2005). Primary prevention criteria include the prophylactic implant for individuals with any cardiac condition that places them at risk for SCA. The criteria that is used for secondary prevention are for individuals who have already experienced a cardiac arrest or sustained life-threatening arrhythmia (Ladwig et al., 2008). As baby boomers age, chronic conditions increase their risk for heart disease and SDA (AHA, 2017), which increases the risk for ICD implants for primary prevention (Ladwig et al., 2008). Individuals living with an ICD never know when they will experience arrhythmia and subsequent shock by the ICD, thus they live with constant uncertainty and fear.

Background

A trauma-informed lens aids in identifying psychosocial factors influencing uncertainty and fear of living with an ICD; this lens can be used to improve psychosocial adjustment and well-being for those individuals. Caring for individuals living with an ICD holistically can be addressed by delineating factors related to the condition, stress appraisal, device acceptance, and social facilitation.

Trauma-Informed Lens

A trauma-informed lens focuses on individual response and adjustment to events and the ability to seek services for situations that may elicit fear and uncertainty (Sweeney et al., 2018). Debilitating psychological distress may persist in ICD patients with perceptions of threat to life, severe condition, stress, or altered psychosocial conditions (Breire & Scott, 2015; Carlson & Dalenberg, 2000; Sweeney et al., 2018). Receiving an ICD can elicit personal feelings of fear, hopelessness, and uncertainty that can undermine the ability to manage life with an ICD (Ford, et al., 2013; Mundy & Baum, 2004). It is identified in the literature that ICD recipients experience lasting psychological effects from the ICD in the form of PTSD (20%), anxiety (40%), and depression (30%) regardless of implant criteria (Ladwig et al., 2008). Care for individuals living with an ICD often focuses on their biological and physical needs and not their psychosocial needs (Donegal & Sears, 2012). Yet, the presence of the ICD can lead to individuals experiencing uncertainty, depending on their condition, stress appraisal, and acceptance of the device. Social facilitation resources can be beneficial in assisting individuals as they react to uncertainty.

Condition

Altered cardiac conditions, such as reduced left ventricular function or a life-threatening arrhythmia, place individuals at risk for SCA and require treatment with an ICD. Patients meeting the criteria for an ICD require ongoing observation and care for a non-reversible chronic altered physical state. Individuals living with the presence of the ICD, a constant reminder of mortality and morbidity, may experience fear and anxiety (Dunbar et al., 2012). There is also the potential danger of a fall or accident occurring when individuals receive a shock, regardless of whether they lose consciousness. Additionally, individuals living with the uncertainty of their

heart condition and ICD treatment may report excessive stress and an altered adjustment (Breire & Scott, 2015). Identifying factors that can assist an individual in living with an ICD will help to improve their return to functioning (Clayton et al., 2018).

Stress Appraisal

Stress emerges as a component for individuals learning to adjust to living with an ICD. Managing stress can take different forms in individuals, depending on the biopsychosocial demands of living with an ICD. Although the physical challenge of adjusting to living with an ICD can be difficult, the psychosocial aspects can be the most taxing on individuals and require additional emotional support (Donegal & Sears, 2012). To restructure the stability of their lives, individuals living with an ICD need to reconcile the fact that they are living with a new normal.

Acceptance

Reliance on technology after receiving an ICD can cause fear and apprehension for individuals regarding their future. Some individuals with an ICD report experiencing uncertainty and stress related to feelings of hopelessness or fear (Dunbar et al., 2012). Uncertainty can cause individuals to experience stress, and the stress can build up to toxic levels if not effectively managed, hindering adjustment to the ICD (Breire & Scott, 2015). Navigating the complexities of technology is essential to moving toward a new life of living with an ICD. Those who express acceptance of the ICD report a positive view of technology and an optimistic attitude toward their new life with an ICD (Ooi et al., 2018).

Social Facilitation

Social facilitation, or the presence, influence, and collaboration with support networks, can impact psychosocial adjustment to an ICD. Social facilitation lessens or exacerbates uncertainty dependent on the effectiveness of social facilitation resources (Clayton et al., 2018).

The presence of individuals or groups who undermine the general physical and psychological health of an individual are ineffective support networks. Responses to living with an ICD may vary with individual social network interactions that influence adjustment.

Methods

Aims

This systematic review aimed to explore psychosocial factors that may influence an individual's living with an ICD through a trauma-informed lens. Psychosocial factors related to uncertainty that may impact adjustment include variability in condition, stress, acceptance, and social facilitation. The purpose of this systematic review was to explore factors influencing adjustment to living with an ICD from a trauma-informed lens to provide a view of psychosocial concerns that may affect well-being.

Design

This review design was a trauma-informed lens to provide a new perspective on living with an ICD from a holistic biopsychosocial approach (Torraco, 2005). Articles addressing the psychosocial adjustment to living with an ICD were analyzed for inclusion. Further evaluation of the articles meeting criteria using the keywords "coping" and "adaptation to assess adjustment" were analyzed for psychosocial adjustment related to condition, stress appraisal, acceptance, and social facilitation. The articles were systematically evaluated for inclusion using PRISMA guidelines and analyzed for quality using the Johns Hopkins Nursing Evidence-Based Practice (JHNEBP) model (Dang & Dearholt, 2017; Page et al., 2021).

Search Methods

The inclusion criteria consisted of studies that were: (a) peer-reviewed, (b) all methods, (c) written or translated to the English language, (d) focused on living with an ICD, e) individual

or family, and (f) focused on adults 18 years or older. Exclusion criteria consisted of: (a) dissertations, (b) non-peer-reviewed articles, and (c) systematic or literature reviews. A search conducted for articles in the databases included CINAHL (EBSCOhost), PubMed, PsycINFO (Ovid), and Google Scholar from 12/2009 through 12/2020 that fit the inclusion criteria for the review. Analysis followed PRISMA guidelines to identify articles for the review (Page et al., 2021). Three searches were conducted and verified by coauthors in the various databases using the following keywords: (a) "implantable cardioverter defibrillator," (b) "living with ICD," and (c) "coping" or "adaptation." Search yields were then examined utilizing criteria for inclusion and exclusion in the review. The first search in CINAHL (EBSCOhost) yielded 43 articles of which 26 articles met the criteria. Next, a search of PubMed produced 49 articles, 10 of which were duplicate articles, and three new articles that were included. The final search of PsycINFO yielded 16 articles of which 10 were duplicates and an additional article for inclusion (Figure 2). The total review yielded 30 pertinent articles that met the purpose and inclusion criteria; two of the articles were excluded due to only the abstract being available, and two were intervention studies. No new articles were identified from the reference review of the 26 included articles. A search in EMBASE using MESH terms related to the key words including "chronic illness," "acceptance processes," "emotional adaptation," or "social adjustment" identified no new articles.

Search Outcomes

Articles were identified during the review utilizing a systematic process. Each article was included in an evidence table in alphabetical order. Headings for the table included (1) "Article," (2) "Purpose," (3) "Design and Measurements" (4) "Setting and Sample," and (5) "Outcomes and Biopsychosocial Factors." Articles were read individually to extrapolate data pertinent to the

purpose of the review through a trauma-informed lens focusing on individual response and psychosocial adjustment to an ICD or feelings of fear and uncertainty. The articles were analyzed for quality and inclusion based on their relevance, reliability, validity, strength, rigor, and pertinence to the purpose of the review (Dang & Dearholt, 2017; Oermann & Hays, 2016). The 26 studies that met the inclusion criteria using PRISMA guidelines included a mixture of qualitative (14), quantitative (11), and mixed methods (1) having pertinent theories and study designs. Of the quantitative studies, one was a longitudinal descriptive correlational design, and five were descriptive cross-sectional designs. Four of the qualitative studies utilized grounded theory, five phenomenological designs, two ethnographic designs, one narrative approach, and one utilized Ricoeur-based data analysis. Articles were selected to allow for saturation of data from various global sources. The studies were conducted in multiple countries including the United States (7), United Kingdom (2), Canada (1), Sweden (5), Netherlands (1), Norway (1), Denmark (1), Italy (3), Spain (2), Singapore (1), and Iran (2). Articles were read a second time to assure they met the purpose of the review and reported biopsychosocial factors which influence living with an ICD.

Quality Appraisal

The articles were of moderate to high quality based on JHNEBP evaluation criteria (Dang & Dearholt, 2017).

Data Abstraction and Synthesis

Data from the included articles were extrapolated (Tables 2.5 and 2.6). Results were categorized based on the completion of a matrix into the main category and six sub-categories (Webster & Watson, 2002). Synthesis of the data was completed using the matrix as a tool.

Results

Viewing the data through a trauma-informed lens provides information on how individuals respond psychosocially to living with an ICD and whether feelings of fear and uncertainty are impacting well-being. Psychosocial adjustment to living with an ICD was addressed in 93% of the studies included in this review. Findings indicate individuals' well-being when living with an ICD requires psychosocial adjustment to related biopsychosocial factors influencing daily life. A matrix was used to identify common categories identified from the data. Factors were categorized under condition, stress appraisal, acceptance, social facilitation, and potential impact on well-being. Factors identified included (1) seeking knowledge, (2) the influence of condition, (3) psychological concerns, (4) living with uncertainty, (5) fear of ICD shocks (6) support networks, and (7) finding a new way of living.

Condition

Seeking Knowledge

In multiple studies, up to 42% of ICD recipients requested knowledge on understanding how the ICD functions, managing stress, regaining activity levels, and planning daily life (Haugaa et al., 2018; Magnusson et al., 2017; Manuel & Brunger, 2016; Mauro, 2010; Ooi et al., 2018). Improving knowledge of the ICD and chronic cardiovascular conditions improved adjustment to living with the ICD. The ICD recovery period was enhanced by new knowledge, behavioral skills, and confidence to promote living with the device (Mauro, 2010; Ooi et al., 2018). Multiple studies reported that individuals received limited information on psychosocial concerns related to their condition or the ICD (Haugaa et al., 2018; Magnusson et al., 2017; Moken et al., 2010; Pedersen et al., 2016). Older individuals reported less need for information

about their device, while younger subjects reported wanting more information to engage in an active lifestyle (Fumagalli et al., 2018; Magnusson et al., 2017).

Influence of Condition

ICD recipients experiencing unpredictable underlying health statuses and comorbidities are at increased risk for psychological concerns due to perceptions of health and the unique needs of their condition (Jakub, 2018; Manuel & Brunger, 2016; Mauro, 2010; Pederson et al., 2016). The severity of left ventricular dysfunction or comorbidities, such as atrial fibrillation, advanced coronary disease, or heart failure, contributed to mild to moderate levels of anxiety and depression (Flemme et al., 2012; Grew, 2017; Paysar et al., 2017; Pedersen et al., 2013: Redhead et al., 2010; Wilson et al., 2013). Several studies reported that ICD recipients experienced feelings of loss of identity, social network, or isolation related to the disruption of the condition or ICD to everyday life (Dehghanadeh et al., 2018; Palacios-Cena et al., 2011). In one study, individuals over age 75 had more concerns with their condition due to the trend of illness severity increasing with age (Fumagalli et al., 2018). Younger individuals expressed not having a baseline to address end-of-life concerns such as having a life-threatening condition that places them at risk for SCA. Recipients living with genetic conditions reported unique considerations related to the uncertainty of living with an ICD at a younger age or passing down the disease (Fumagalli et al., 2018; Magnusson et al., 2017).

Primary prevention indication for an ICD, with normal baseline psychological status, correlated with fewer ICD concerns and less anxiety (Pederson et al., 2013). Patients who received ICD implants after cardiac arrest, secondary prevention indication, were more likely to have a negative recovery response and a higher incidence of depression (32%), and PTSD (28%), even with a stable underlying condition (Isreaelson et al., 2018; Pasyar et al., 2017; Presciutti et

al., 2019). Individuals who received an ICD after cardiac arrest identified as feeling vulnerable and had more concerns regarding engaging in activity (Pedersen et al., 2016).

Stress Appraisal

Psychological Concerns

Mauro (2010) conducted a 9-year longitudinal study finding psychosocial adjustment levels did not significantly change over time, with early psychological adjustment at 2 months post-ICD implant explaining 40% of the variance. Psychosocial adjustment to living with an ICD positively correlated with optimism and stable mental health (Dehghanzadeh et al., 2018; Flemme et al., 2012; Grew, 2017; Ooi et al., 2018). Optimism was the most frequently used strategy for living with an ICD (Flemme et al. 2012; Humphreys et al., 2016). In a study conducted at 12 months on the psychological health of 332 ICD recipients in the Netherlands, most subjects (72.8% - 81.7%) maintained their level of psychological functioning at 12 months post-ICD implant (Hammash et al., 2019).

In contrast, the presence of psychological distress correlated with the perception of ICD treatment as a stressor (Ooi et al., 2018). Younger individuals reported more psychological burdens related to the device (Fumagalli et al., 2018; Magnusson et al., 2017; Wilson et al., 2013), possibly due to less perceived psychosocial control within the environment (Hammash et al., 2019). Higher anxiety, depression, ICD concerns, and lower social support predicted lower perceived control (Flemme et al., 2012; Hammash et al., 2019; Pederson, et al., 2013). Women had an increased risk for anxiety in multiple studies accounting for 26% of the variance in adjustment (Flemme et al., 2012; Wilson et al., 2013). Several studies on the presence of a Type D personality, defined as having negative perceptions and outlook, correlated with a

deterioration of psychological health (Israelsson et al., 2018; Pedersen et al., 2013; Pedersen et al., 2016).

Living with Uncertainty

Individuals reported feeling uncertain due to disrupted daily routines, family roles, and social networks, and potential future adjustment to fear and a loss of control (Dehghanzadeh et al., 2018; Flemme et al., 2012; Jakub, 2018). Men experienced more uncertainty and complexity living with an ICD (Mauro, 2010). Up to 50% of ICD recipients did not return to previous work situations (Fumagalli et al., 2018). Workplace changes potentially affected emotional adjustment to the ICD due to loss of prestige, identity, or income, and changes in roles, routines, or family dynamics (Fumagalli et al., 2018; Israelsson et al., 2018; Magnusson et al., 2017; Pasyer et al., 2017). Younger ICD recipients noted a loss of identity due to health concerns affecting participation in everyday leisure and work activities (Fumagalli et al., 2018; Magnusson et al., 2017). Individuals who reported living with ambiguity and uncertainty, especially surrounding fear of shocks, indicated knowledge and support as beneficial to restructuring life and regaining control (Dehghanadeh et al., 2018; Flemme et al., 2011; Mauro, 2010; Morken et al., 2010; Palacios-Cena et al., 2011; Pasyar et al., 2017). The risk of death and an uncertain future correlated with emotional responses of feeling vulnerable, uncertain, anxious about shocks, and depressed (Humphreys et al., 2016; Pasyar et al., 2017). Engaging in planned activities, building knowledge, and incorporating the ICD into daily life helped alleviate feelings of fear and uncertainty (Mauro, 2010; Ooi et al., 2018).

Fear of ICD Shocks

Most ICD recipients who did not receive shocks did not appraise concerns with daily living or identify stressors and had a moderate perception of control over their lives (Flemme et

al., 2012). Ambivalence over ICD treatment occurred between knowledge of ICD as a lifesaver and fear and uncertainty of receiving a shock (Haugaa et al., 2018; Mauro, 2010; Morken et al., 2010; Ooi et al., 2018). Fear of elevating the heart rate with exercise and receiving multiple or unexpected shocks were identified as reasons for feeling vulnerable, avoiding activity, and having lower levels of perceived control (Cutitta et al., 2014; Garrino et al., 2018; Hammash et al., 2019; Humphreys et al., 2016). Living with uncertainty regarding shocks and having a pessimistic attitude were found to create a disabling cycle of loss of control and support resulting in a deterioration in psychological functioning (Morken et al., 2010; Pederson et al., 2013). Although all age groups were found to have similar levels of depression and anxiety at baseline, experiences with ICD shock precipitated chronic anxiety and higher depression levels (Hammash et al., 2019; Redhead et al., 2010). African American ICD recipients displayed higher device-related distress and shock anxiety than White recipients (Wilson, et al., 2013).

Acceptance

Acceptance of ICD

Acceptance of the ICD was noted as a necessary part of living with an ICD and central to psychosocial adjustment (Grew, 2017; Manuel & Brunger, 2016). Although most patients did not regret the implant, 30% to 40% had some worry about the presence of the device (Fumagalli et al., 2018; Haugaa et al., 2018). Individuals had higher levels of ICD acceptance when they were optimistic about the benefit of having the device. Lower levels of ICD acceptance were found in individuals with body image concerns or device-related distress (Flemme et al., 2012; Fumagalli et al., 2018; Haugaa et al., 2018). Other studies correlated higher levels of positive ICD acceptance with increased knowledge of the ICD, less shock anxiety, fewer comorbidities, and inclusion of religion in an individual's lifestyle (Dehghanzadeh et al., 2018; Ooi et al., 2018;

Wilson et al., 2013). The strongest negative predictors of ICD adjustment were the presence of shock, anxiety, and depression (Hammash et al., 2019; Redhead et al., 2010; Wilson et al., 2013).

Social Facilitation

Supportive Networks

Social support from significant others and consistent, expert health professionals improved psychosocial adjustment to living with an ICD for individuals and partners (Manuel & Brunger, 2016: Ooi et al., 2018; Pederson et al., 2016). Support from family facilitated their psychosocial adjustment by overcoming physical, emotional, financial, or relational barriers to recovery (Dehghanadeh et al., 2018). ICD recipients over 70 years of age tended to hold onto customs related to their identity and utility in their social and personal lives. They also reported feeling isolated by their health process and status, leading to perceptions of a loss of independence. Continuing routines and daily living habits promoted normalcy for this age group (Fluur et al., 2013; Ooi et al., 2018; Palacious-Ceda et al., 2011).

Significant Others

ICD recipients expressed fear of hypervigilance from spouses over their health status and reported often feeling isolated from their families (Fluur et al, 2013; Humphreys et al, 2016). The need for an ICD increased spousal anxiety (Redhead et al., 2010). Spouses reported feeling left out of involvement in their partners care and education; therefore, they requested information on managing their partners' illness trajectory, role changes, warnings signs of deterioration in health, and ICD shock (Fluur et al., 2010; Pasyar et al., 2017). Working with spouses as partners was more effective in improving self-efficacy and technological knowledge for ICD recipients and their spouses and relieving caregiver burden. Spouses of different age groups had varying

concerns related to work, social life, and intimacy. Many spouses utilized outside support networks for their needs and to identify the needs of their spouses (Ooi et al., 2018).

Healthcare Professionals as Social Support

ICD recipients expressed frustration with lack of continuity of care from care received outside of their healthcare ICD team, especially during times of crisis or shocks (Magnusson et al., 2017). Supportive communication from a consistent, expert healthcare team helped with developing strategies for daily life (Flemme et al., 2011; Magnusson et al., 2017; Manuel & Brunger, 2016). Response to remote monitoring as a solution to consolidate care was mixed (Grew, 2017; Pedersen et al., 2016). Individuals requiring complex care, such as after cardiac arrest, had more face-to-face interactions with healthcare teams (Israelsson et al., 2018). In a multinational quantitative study on cardiac devices, n=1644, 83% of individuals had face-to-face follow up and 51% preferred that form of connection (Haugaa et al., 2018). Mentoring relationships reportedly enhance individualized care and return to activity. ICD recipients expressed trust in healthcare providers but often sought psychosocial assistance outside of established health professional relationships or joined support groups (Fumagalli et al., 2018; Garrino et al., 2018).

Potential impact on Well-Being

New Way of Living

Foundationally, individuals expressed a desire to return to their pre-ICD life (Grew, 2017; Palacios-Cena et al., 2011). Finding a new way of living with an ICD correlated with reshaping views of ICD risk as an opportunity and incorporating alternative ways of living with the ICD (Dehghanzadeh et al., 2018; Grew, 2017: Pasyar et al., 2017). Although most ICD recipients did not appraise daily concerns or perceived stressors in living with an ICD (Flemme

et al., 2012), daily routines and habits needed to be adjusted to daily life with an ICD (Dehghanzadeh et al., 2018; Garrino et al., 2018; Ooi et al., 2018; Palacios-Cena et al., 2011). Men tended to return to normalcy by avoiding talking about the ICD, promoting an illusion of good health, and being independent (Jakub, 2018). Avoidance behaviors were utilized by limiting activity (Cutitta et al., 2014; Morken et al., 2011; Magnusson et al., 2017), even when individuals reported the ability to engage in activities (Cuttitta et al., 2014). Younger individuals were more negatively impacted by the ICD related to perceptions, activity level, loss of intimacy, and work options (Fugamalli et al., 2018; Magnusson et. al, 2017). Structured planning was found to alleviate feelings of uncertainty and build confidence in adjusting to activities and living with an ICD (Humphreys et al., 2016; Ooi et al., 2018).

For many older individuals, health-related quality of life **(**HRQoL) improved after the ICD (Fumagalli et al., 2018; Haugaa et al., 2018). Cardiac arrest survivors reported improved HRQoL and less pain or discomfort (Presciutti et al., 2019). Diminished HRQoL correlated with individuals who were unemployed, younger, a Type D personality, and female, and having more comorbidities and feeling less in control (Israelsson et al., 2018; Mauro, 2010; Pedersen et al., 2013; Pedersen et al., 2016).

Discussion

Adjusting to living with an ICD can be influenced by fear, hopelessness, and uncertainty, especially in the presence of ICD shocks, severe conditions, comorbidities, or a history of mental health challenges (Donegal & Sears, 2012). ICD technology is a significant advancement in medical care and saves lives. However, ICD shocks are unpredictable and painful, and living with an ICD can be stressful. Using a trauma-informed lens for care delivery promotes a therapeutic, holistic approach to care to provide safety and security during adjustment (Harris &

Fallot, 2001). Psychosocial education and support for current treatment may alleviate or minimize uncertainty when living with an ICD. The presence of symptoms that affect living with an ICD needs to be screened, evaluated, and addressed early to prevent the debilitation of the individual or family.

Some stress reaction is typical for individuals who have a potentially life-threatening cardiac condition and need an ICD (APA, 2013; Breire & Scott, 2015). Even resilient individuals who receive an ICD have the potential for short-term stress reactions (Bonanno & Mancini, 2008). Early screening of recipients before the ICD implant is recommended to detect and intervene on any negative outlook or psychological distress and enhance psychosocial adjustment (Flemme et al., 2011; Mauro, 2010; Redhead et al., 2010; Hammash et al., 2019; Pedersen et al., 2013). Detection allows time to intervene and improve perceived control, sense of identity, and lifestyle concerns for recipients at higher risk for maladjustment following ICD placement (Alonso-Ferres et al, 2020; Ferguson, & Goodwin, 2010). Individuals' assessments for maladaptive responses should include screening for the presence and level of stressors, ICD shocks, symptoms, social support, and optimism. Severe health-related stressors can cause individuals with an ICD to experience low levels of chronic depression or anxiety; therefore, it is critical to screen for depression and anxiety and provide treatment accordingly (Bonanno & Mancini, 2008). Recipients of an ICD experiencing chronic maladaptive behaviors require careful consideration for referral and options for treatment.

Personality screening should be included in a psychosocial assessment. Optimism is a protective factor and should be encouraged, with additional psychological support required for pessimistic individuals. Pessimistic individuals are potentially a Type D personality (D stands for distressed) who tends to be prone to worry, sadness, a pessimistic outlook, negative self-talk and

avoidance of social situations (Clark, 2021). People predisposed to being Type D may not adjust well to life with an ICD and need increased psychosocial support.

Psychosocial well-being for adults living with an ICD can improve through addressing the factors that could cause uncertainty. Treating recipients of an ICD and their underlying condition necessitates finding new strategies for living. Individuals with an ICD should be encouraged to seek (a) knowledge about the ICD, (b) a safety plan for ICD shocks, (c) an optimistic outlook, (d) increased social support, and (e) strategies for living with an ICD. ICD education for individuals and families should include psychosocial and cognitive information about ICD therapy to facilitate adjustment (Yildiz et al., 2018). Including psychosocial education within the plan of care would help individuals to identify their care needs, adjust to living with an ICD, and seek support. The literature reveals that shocks, which are very painful and occur with no warning, can be significant stressors in living with an ICD. Individuals who have the ICD placed prophylactically, and have not experienced a shock, have higher levels of adjustment to living with an ICD; but their adjustment to the ICD may regress if they experience a shock (Borne et al., 2017). Patients with a higher risk of shock are at greater risk for experiencing depression, anxiety, uncertainty, and fear and to require support. Enhancing adjustment to life with an ICD requires informing individuals about the importance of contacting their physician if a shock occurs. Healthcare providers need to assess the recipient's condition and schedule follow up regarding psychosocial adjustment and adherence to a treatment plan. To avoid becoming sedentary and experiencing shocks, treatment plans need to include education on cardiac medications and return to activity.

Social facilitation can act as a buffer to symptoms and stressors for individuals with an ICD; therefore, an effective social support network can provide encouragement and enable the

development of new patterns of living. Support networks comprised of family, friends, and health care professionals are essential in navigating the challenges of living with an ICD and promoting psychosocial adjustment. When identifying potentially stressful symptoms, caregivers should evaluate the individual with an ICD and their family response. Family and other supporters of the recipient should routinely receive information on living with an ICD and shocks. Social support from a secure family network may help to facilitate psychosocial adjustment. When a family member receives an ICD, role changes affect the whole family. Therefore, family networks should encourage individuals with an ICD to engage in exercise, supportive relationships, and role adjustments. Support groups are an informal way for individuals and their families to receive valuable information on lifestyle adjustment. Networking with an interdisciplinary health team may facilitate those new patterns of living. The interdisciplinary health care team may do this by enhancing the recovery of the recipient of an ICD by providing support to boost their resilience, reduce stress, and improve social relationships (deRoon-Cassini et al., 2010). Additionally, the healthcare team can facilitate the ICD recipients' action toward well-being, to enhance their adjustment and alleviate symptoms related to ICD treatment.

Limitations

The search strategy incorporated may not have captured every study that met the inclusion criteria due to the keywords chosen and its limit to a 10-year timeframe. In addition, the review did not include studies testing interventions; therefore, conclusions on the use of the information for suggesting interventions is limited.

Future Research

Research is necessary on specific strategies to assist people with an ICD while adjusting to ICD shocks. The sophisticated technology in health care is often associated with difficulty in adjustment. It is essential to research recipient experiences with adjustment to an ICD and potential interventions for promoting adjustment. Research is needed that focuses on the best strategies for supporting individuals and families with role transitions related to lifestyle changes following an ICD. Finally, more research to improve adjustment to the ICD technology, including remote monitoring, would be beneficial in varied urban and rural settings.

Conclusion

This study provides a unique trauma-informed perspective on how a threat to life, underlying condition, and stress influence adjustment to an ICD and recovery from shocks. This perspective using a trauma-informed lens expands the much-needed literature on the influences of psychosocial factors on living with an ICD. Interdisciplinary teams need to screen ICD recipients early to identify underlying psychosocial concerns for prompt intervention that may improve adjustment and well-being.

Table 2.4

Systematic Review: Quantitative Studies

Study	**Purpose**	**Design /Measurements**	**Setting / Sample**	**Outcomes and Biopsychosocial Factors**
Cutitta et al., 2014 Level III High Quality	Examine avoidance of activity and exertion after ICD shock	Descriptive using DASI, Modified DASI: Avoidance	United States n=443 Medtronic ICD database	*Stress Appraisal and Acceptance* Unable to engage in strenuous activity (68.8%), sex (35.4%), short run (49.0%) Able to engage in activity but avoided ~strenuous activity (76.1%) ~sexual activity (64.6%) but avoided (51.0%)
Flemme et al., 2012 Level III High Quality	Describe effectiveness of coping strategies with ICD and explore factors influencing coping	Cross-sectional survey 6 to 24 months after ICD implant using Jalowiec Coping Scale-60, HADS, CAS, Quality of Life Index – Cardiac Version	Sweden n=146 Multicenter	*Condition* Comorbidities: Ischemic heart disease (52%), heart failure (38%), atrial fibrillation (25%) Secondary prevention indication (53%), ICD shocks (26%) *Stress Appraisal* Anxiety (p=.001) and gender (p=.046) accounted for 26% of variance in use of coping; strategies seldom used Depression positively associated with evasive coping (p=.01) Most reported moderate perception of control; low levels of control (28.4%) associated with fatalistic coping (p=.009) Most frequent coping strategies: emotional (optimism, self-reliant, fatalistic) and problem-focused (confrontive) Most effective coping strategies: optimistic, supportive, confrontive, palliative Least helpful coping strategies: emotive

Fumagalli et al., 2018 Level III High Quality	Evaluated concerns and perceptions of psycho-logical effects, end-of-life, HRQoL with any type cardiac implantable electronic devices (CIED) based on age	Prospective study	Italy n=437 Focus Italian data Multicenter, Multinational, from seven countries Total n=1646 Age defined: Older age >75 years Younger age <75 years	*Condition* Device use more common in older age, majority choose pacemaker over ICD, Pacemaker 58.1%, ICD 27.7% 90% did not have device related complications Inverse relationship age and negative impact on life activities Younger age: ~impacted more negatively in daily life and activity (p=035), affected professional (p=.001) and personal life (p=.033), and felt limited (p=.001) ~want knowledge of device effect on living: psychological (p=.035), physical (p=.001), sexual (p=.001), or driving (p=.003) Older age: ~more concern about severity of disease with age ~need less information (p=.044) ~HRQL improved more with device (p=.001) Any age: ~had (84.8%) or preferred (56.5%) face-to-face visits ~no discussion pre-ICD end-of-life issues (69.7%) ~after implant no ICD plan if condition worsens (50.7%) *Acceptance* Majority did not regret implant *Stress Appraisal* 30% some device worry *Social facilitation* Younger age wants social support groups with same type device
Hammash et al., 2019 Level III High Quality	Determine relationship between perceived control and HRQoL for ICD recipients	Cross-sectional using CAS-R, EQ-5D, HADS, MPSSS, ICDC, EOL-ICD	United States n=190 Australia n=73 Total n=263 Multicenter at four outpatient clinics	*Condition* ICD Shock: ~Over 1/3 had ICD shock ~three times reduction in activity after ICD shock ~4.66 times higher rate depression ~two times lower perceived control Reported pain: ~11.4 times more often with anxiety ~three times more often with lower perceived control *Stress Appraisal* Psychosocial factors: ~depression (25%) and anxiety (18%)

				~28% variance perceived control (p<.001) ~Perceived control 27% variance HRQoL (p <.01) ~Lower perceived control (p<.01), higher levels depression (p <.01) and anxiety (p<.05) predicted lower levels HRQoL Lower levels of perceived control: ~higher anxiety scores (p<.05), depression scores (p<.05), ICD concern scores (p<.05) *Social facilitation* Lower perceived control with lower social support (p<.01)
Haugaa et al., 2018 Level III High Quality	Analyze knowledge, experiences, and attitudes toward cardiac implantable electronic devices (CIED)	Prospective survey	Poland (49%) Italy (26%) n=1644 Multicenter and multi-national, age > 50 years	*Condition* Request information (42%): ~Physical limitations, living with device, procedures, physical activity, reducing stress Informed of potential complications: ~Prior to device implant (57%), received some (29%), insufficient (14%) Self-reported complications (9%): infections (4%) When complications occurred: ~Were informed (72%), sufficiently informed (44%), insufficiently informed (28%) Discussions on End of life or terminal illness: ~Not discussed (66%), remain active (6%), deactivate (5%), no preference (2 %,), did not want to discuss (18%) ~Discussion with provider: none (84%), brief (12%), complete review (5%) *Acceptance* Regret implant (7%), did not think about (24%) *Stress Appraisal* Device-related issues: ~None (64%), fear of shock or life interference (36%), actual interference with daily life (6%), concerns about device (40%), diagnostic procedures (12%), personal life (7%), professional (4%), insurance (2%), pregnancy (0.4%) *Social facilitation* Follow-up: ~Face-to-face (83%): less frequent (11%), as needed (4%); remote (17%)

				~Patient follow-up preference: regular onsite visits (51%), see physician (27%), remote (15%)
Israelsson et al., 2018 Level III High Quality	Explore factors associated with HRQoL of cardiac arrest subjects with an ICD in relation to gender, with comparison to general population	Cross-sectional, correlational, and comparative, secondary analysis using EQ-5D-3L, HADS, ICDC, CAS, DS14	Sweden n=990 Cardiac arrest survivors	*Condition* Cardiac arrest compared to general population: ~Better HRQoL (p=.001), less pain (p=.001), more mobility issues (p=.002) and usual activities (p<.001) ~ICD shock (40.2%) Worse HRQoL with unemployment and more comorbidities Women compared to men: ~Younger (p<.001), working (p<.001), longer time since implant (p<.001), less comorbidities (p=.009), *Stress Appraisal* Anxiety (15.5%), depression (7.4%), Type D personality (14.5%) Women compared to men: ~More ICD concerns (p=.032), less perceived control (p=.015), more anxiety (p=.002), lower HRQoL (p=.003) Worsened HRQoL: ~With less perceived control, female gender, having ICD related concerns, and Type D personality
Mauro, 2010 Level II High Quality	Measure change over time of relationship between uncertainty and psycho-social ICD adjustment	Longitudinal, descriptive, correlational using PAIS-SR, MUIS	United States n=21 Four teaching hospitals Followed 9.4 years	*Condition* Not on antiarrhythmic medications (62%) Men more complexity living with ICD (p=.002) *Acceptance* Early adjustment at 2 months explained 40% variance in adjustment over time (p=.010); No significant change in uncertainty and adjustment levels over time (p= .003) *Stress Appraisal* Men experienced significantly more uncertainty (p=.009)
Pederson et al., 2013	Examine psychological health at 12 months post ICD implant	Correlational, descriptive survey pre-implant and 12 months using	Netherlands n=332 First time implant of ICD or CRT-D	*Condition* Primary prevention (63.9%): ~Less ICD concerns (p=.03), anxiety (p=.006) Comorbidities: Coronary disease (57.8%), heart failure (39.8%), atrial fibrillation (22.9%)

Level III High Quality	and factors influencing deterioration	ICDC-Dutch version, HADS, DS14		~Left ventricular dysfunction (p=.007) and atrial fibrillation (p=.02) Medication use: ~Amiodarone (18.4%), betablocker (79.5%) ~On betablocker for shock (59.5%) or no shock (82.4%) (p=.001) ICD shocks (12.7%): ~explained variance ICD concerns (5.1%), anxiety (3.1%), depression (3.5%) *Stress Appraisal* Majority (72.8% - 81.7%) maintained level of psychological functioning at 12 months, deteriorated function predicted by ICD shock and Type D personality (p<.05) Psychological status baseline and 12 months: ~ICD concerns (30.1%, 15.4%), anxiety (24.1%, 15.7%), depression (22.9%, 20.8%); clinical distress unchanged (9.1 to 12.7%), Older age (p=.04) reduced anxiety at 12 months
Presciutti et al., 2019 Level III High Quality	Determine associations of depression and PTSD in cardiac arrest survivor long-term recovery perceptions	Cross-sectional, descriptive using BRANS, CES-D, PCL-S, M-IADL, CCI	United States n=78 Cardiac arrest survivors	*Condition* Cardiac arrest had no significant differences in those with positive or negative perceptions Dependent one or more activity of daily living (64.1%) *Stress Appraisal* Depression (80%), PTSD (73%) had negative recovery perception Persistent negative recovery perceptions zero to six months At 6-month negative recovery perceptions (53%), depression (32.1%), PTSD (28.2%) More dependence with negative recovery perception (p=.06)
Redhead et al., 2010 Level III High Quality	Determine incidence of anxiety and depression post ICD after MI, effects of comorbidity and shocks	Cross-sectional with control groups using HADS, MOS SF-36	United Kingdom n=100 ICD recipients n=109 Spouses	*Condition* Experience of ICD shocks increased anxiety (p=.03) with differences in no shock (p=.02), one shock, 3 or more shocks (p=.001) and no differences in depression *Stress Appraisal* For all groups: anxiety (24-34%) and depression (14-22%) Participant need for ICD increases spousal anxiety (47%) similar with other groups (p=.31) indicating high spousal anxiety for all cardiac patients Low use of medication treatment for patient or spouse for anxiety (13%), depression (7%)

Wilson et al., 2013 Level III High Quality	Investigate factors related to recipients' acceptance of ICD, focus on examination of racial and gender differences	Cross-sectional, descriptive using FPAS, FSAS, ESSI, HADS, Duke Religion Index, Hoge Intrinsic Religiosity Scale	United States n=101 Outpatient clinics	*Condition* Primary prevention (91%), one or more ICD shocks (51%) White (58%), African American (AA) (42%), Baptist (45%) Comorbidities: coronary disease (54%), hypertension (44%), diabetes (33%) AA were younger (p=.003), value on religion (p=.490) and lower ICD knowledge (p=.03) than Whites *Acceptance* High acceptance ICD (80.9%), whites more accepting (p=.14) Race, age, comorbidities, religion, social support, anxiety, depression, shock anxiety, and ICD knowledge accounted for 66% variance in acceptance of ICD Strongest predictors of device acceptance were shock anxiety (p=.001), depression (p=.01), and ICD knowledge (p=.001) *Stress Appraisal* AA had higher distress (p=.001), shock anxiety (p=.002)

Measurement tools: Duke Activity Status Index (DASI), Charlson Comorbidity Index (CCI), Patient Concerns Assessment (PCA), State-trait Anxiety Inventory (STAI), Health Related Quality of Life (HRQoL), Control Attitude Scale-Revised (CAS-R), EuroQol-5D (EQ-5D, Hospital Anxiety and Depression Scale (HADS), Multidimensional Perceived Social Support Scale (MPSSS), ICD Concerns Questionnaire (ICDC), End-of-Life Issues in ICD (EOL-ICD), EuroQol-5D-3 level (EQ-5D-3L), Hospital Anxiety and Depression Scale (HADS), ICD-related Concerns (ICDC), Control Attitudes Scale (CAS), Type D Scale (DS14), Psychosocial Adjustment to Illness Scale-Self-Report (PAIS-SR), Michel Uncertainty in Illness Scale (MUIS), Repeatable Battery for the Assessment of Neurological Status (BRANS), Center for Epidemiological Studies-Depression Scale (CES-D), PTSD Checklist-Specific (PCL-S), Independence in instrumental activities of daily living (M-IADL), Medical Outcomes Study Short-Form 36 (MOS SF-36), Florida Patient Acceptance Survey (FPAS), Florida Shock Anxiety Scale (FSAS), Social Support Instrument (ESSI).

Table 2.5

Systematic Review: Qualitative and Mixed Methods Studies

Study	**Purpose**	**Design / Measurements**	**Setting / Sample**	**Outcomes and Biopsychosocial Factors**
Dehghan-zadeh et al., 2018 Level III High Quality	Exploring living with a CRT-D with a history of heart failure	Grounded theory using Semi-structured interviews	Iran n=17 men (n=9) women (n=8) One Clinic	*Condition* Lose independence and health request to gain more knowledge Empowered by work *Acceptance* Loss of integrity due to spirituality and doubtful acceptance Coexisting helps find facilitators to new life; best is optimism Empowered by social networks *Stress Appraisal* Threat to comfort and ability to manage stress Uncertainty generates fear and sense of loss of control
Flemme et al., 2011 Level III High Quality	Explore individuals living with ICD and handling daily life	Grounded theory Interviews, Baseline demographics and clinical variables obtained	Sweden n=16 men n=9 women n=7 ICD for 6 to 24 months, Four Hospitals	Core Theme: Incorporating uncertainty into daily life *Condition* Strategy to handle uncertainty is to restrict activity ICD and health condition are disruptive Increased vulnerability with unpredictability *Acceptance* Strategy to handle uncertainty is to accept ICD and reevaluate life Acceptance by building trust and dependence on support *Stress Appraisal* Distraction as strategy to handle uncertainty Attempt to balance control over life and fear Reevaluating purpose in life and emotional response

Fluur et al., 2013 Level III High Quality	Explore spouse's reflections on living with ICD focused on end-of-life and palliative care	Content Analysis Approach using in-depth interviews	Sweden n=18 men (n=7) women (n=11) Spouses of medically stable ICD recipients with implant > 6 months, Five Clinics	*Condition* Dealing with daily life changes Wanting to be involved with knowledge, visits, emotional support Manage relationship including role changes, avoidance, intimacy Alert to warning signs: safety plan Living with uncertain future Worry about decline partner health, loss of control, hypervigilance Anticipating ICD shocks and have a plan, learn CPR Death or serious illness seldom discussed with professionals or spouses Spouses of different age groups may have different concerns
Garrino et al., 2018 Level III High Quality	Explore ICD recipients' experiences to improve adaptation and quality of care	Descriptive phenomeno-logical method using patient narrative approach	Italy n=20 men (n=15) women (n=5) Coronary intensive care unit (CCU)	*Condition* Relying on technology: alone but protected, safety Knowledge on living with device; adequate on technology, lacking on daily life and adjustment ICD for a genetic disease brought family guilt of heredity *Acceptance* Coping with effects on daily life: support *Stress Appraisal* Coping with Anxiety Living in constant state of fear ~Fear of ICD shock: violent and uncertain, ambivalence ~Fear of death: vulnerable and uncertain
Grew, 2017 Level III High Quality	Evaluate the introduction of ICD therapy and risk of sudden death	Ethnographic using Clarke's situational analysis using two groups, 1. informal conversation and 2. in-depth conversation	Denmark Group 1: Clinician n=30, Patient n=40 Group 2: Clinician n=5, Patients n=12	*Condition* Clinicians present device as safety from sudden death; reducing risk of death, longer life Patients want life without severe heart disease, fear of shocks, or changes to daily life or lifestyle Risk of shocks, remote monitoring, severity of disease *Acceptance* Loss of Status *Stress Appraisal* Loss of control or status Sense of security

Humphreys et al., 2016 Level III High Quality	Explore the lived experiences of ICD	Semi-structured interviews using Braun and Clarke guidelines	United Kingdom n=18 ICD recipients who did or did not receive a shock	*Condition* Physical consequences *Acceptance* Acceptance in a year varied by definition of acceptance *Stress Appraisal* Emotional consequences: feeling vulnerable and uncertain; anxiety and depression Concealed feelings from family to limit overprotection or protect others' emotional well-being Coping strategy: avoidance or regain control over life
Jakub, 2018 Level III High Quality	Examine adjustment to living with an ICD by men	Ethnographic study	United States n=12 ICD implant at least 4 years with at least 1 replacement	*Condition* Chronic illness image: health severity, age, view of ICD Return to normal life and activity, denial of health concerns, independence *Stress Appraisal* Maintain masculine image: attention and activity restrictions, illusion of good health, cultural norms, reject overprotection
Magnusson et al., 2017 Level III High Quality	Describe experiences of HCM patients with ICD	Interviews using Hermeneutics and Latent Content Analysis	Sweden n=26 primary indication (n=20) secondary indication (n=6)	*Condition* Evaluate Hypertrophic Cardiomyopathy symptoms, medications, timing of implant, genetic condition at younger age, activity restriction, knowledge provides assurance, inappropriate shocks, feel healthy *Acceptance* Accepting the ICD as a need to survive Younger age different concerns, professional life, insurance *Stress Appraisal* Evaluate worries Family support strong with some overprotection
Manuel & Brunger, 2016 Level III High Quality	Examine the lived experiences with an ICD with genetic disorder	Grounded theory using semi-structured interviews	Canada n=15 men (n=8) women (n=7)	*Condition* Adjust to ICD function and genetic disorder *Acceptance* Living with everyday challenges Coping depends on reshaping views of risk and narrative

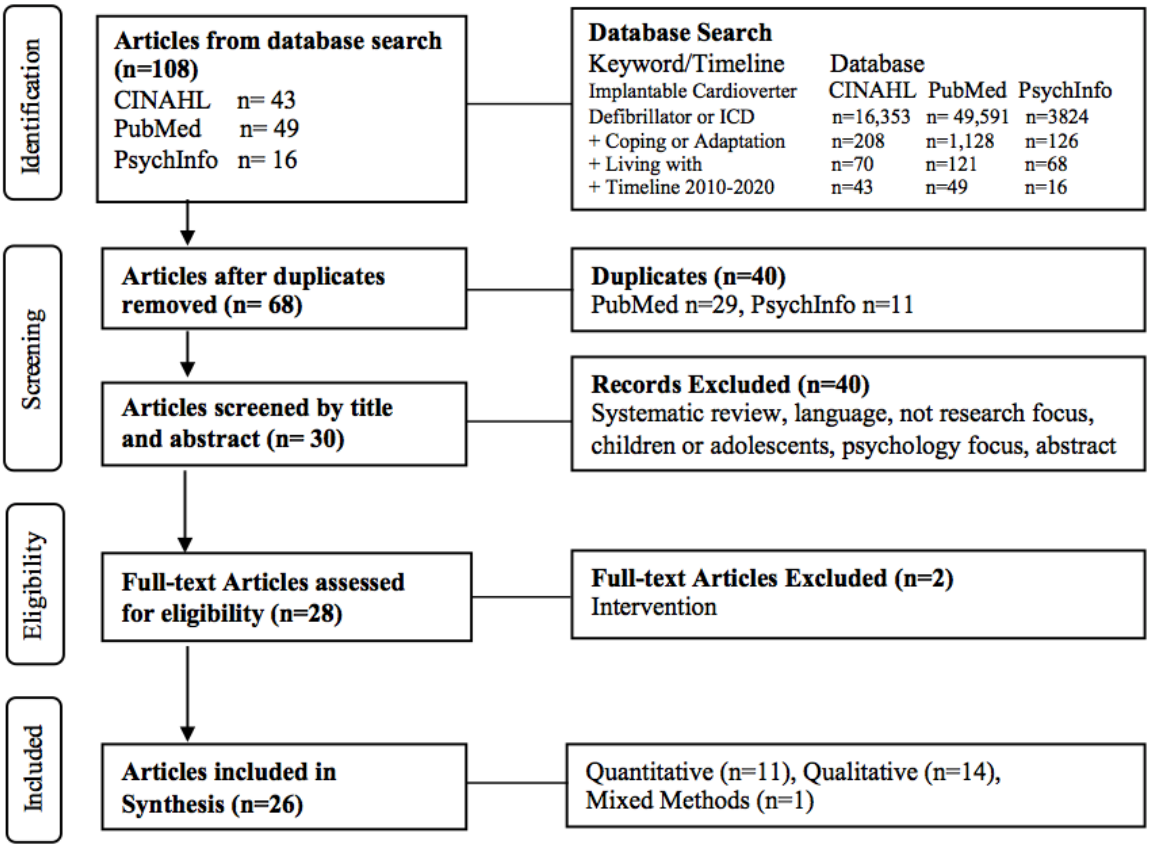
Morken et. al., 2010 Level III High Quality	Explore ICD recipients' experiences living with device over time	Grounded theory using Semi-structured interviews	Norway n=16 men (n=11) women (n=5) Hospital, ICD at least 10 months	Reconstruct unpredictability *Condition* Losing control: uncertainty after shock affects partner relationship, reduce physical activity Lacking support: need continuity of care and knowledge *Acceptance* Regaining control: acceptance of device, trust of technology *Stress Appraisal* ICD shock cycles prior coping backward to loss of control *Social Facilitation* Seeking support: family to share feelings and improve activity
Palacios-Ceña et al., 2011 Level III High Quality	Determine experiences of Spanish ICD recipients	Unstructured and semi-structured interviews	Spain n=6 n=20	*Condition* Developing Strategies: adjust to daily life, yearning for old life, avoidance, seeking knowledge, religion *Acceptance* Accepting the Change: mobility, independence, family, work ICD as life protection Ambivalence toward ICD *Stress appraisal* Continuous uncertainty and waiting, anticipation of shocks Transformed: Refection on meaning of life, end-of-life *Social Facilitation* Rethink partner relationship: emotionally distant, closer to spouse, sexual intimacy Give up independence: family assistance. overprotection
Palacios-Ceña et al., 2011 Level III High Quality	Describe the experience of elderly Spanish men with an ICD	Phenomeno-logical using unstructured interviews and personal accounts	Spain n=20 Older age over age 70	*Condition* Develop strategies: continue routines and habits of daily living Internal and external change in worldview *Acceptance/Stress Appraisal* Accept change, living and feeling safe Perceive change and adjustment as loss of independence *Social Facilitation* May be isolated, feel imprisoned by health process or feel transformed, hold identity through customs and social life Partners important in culture

Pasyar et al., 2017 Level III High Quality	Identify and describe patient experiences with living with an ICD	Interpretive Phenomeno-logical approach using semi-structured interviews, analysis using Van Manen's proposed stages	Iran n=10 men (n=6) women (n=4)	*Acceptance* Compromised self-identity: loss of prestige, unpredictability, acceptance, dependence, new social and work life *Stress appraisal* Crossing border of unknown: ambiguity and uncertainty ICD and condition, facing death, fear and anxiety Fluctuating path adjustment: face death versus normal life *Social Facilitation* Surrounded by changes: routines, roles, family dynamics, social changes toward self-care
Ooi et al., 2018 Level III High Quality	Explore perceptions of living with ICD towards quality of life, coping strategies, and learning needs	Qualitative Exploratory study design using semi-structured interviews	Singapore n=16 men n=13 women n=3	*Condition* Physical coping: self-care and seeking information Need for information: end-of-life decisions *Acceptance* Ambivalent relationship with ICD: view as life-saving Acceptance and return to normalcy: new life, self-concept *Stress Appraisal* Experiencing ICD shocks: related to fear, distress Emotional coping: reduce stress, optimism, fatalism, religion *Social Facilitation* Receiving support: healthcare professionals advocates, managers, information, family emotional and social Cultural power dynamic with provider
Pedersen et al., 2017 Level III High Quality	Exploration of patient needs and preferences for remote monitoring	Mixed-Methods design questionnaires and focus group interviews, survey with ICDC, DS14, PHQ-9	Denmark n=389 First time implant of ICD or CRT-D within last two years in adults >18 years	*Condition* High satisfaction with information given, 13.1% dissatisfied No information on psychological support for patients (39.9%), relatives (41%), deactivation end-of-life (47.8%) Top five care concerns: continuity of care (75.2%), timely remote monitoring feedback 61.1%), personal contact (59.6%), test physical activity (52.5%, staff ask how hospitalization went (50.4%) *Stress Appraisal* Secondary prevention, cardiac arrest request psychological support after discharge, vulnerable group

Measurement tools: ICD Concerns Questionnaire (ICDC), Type D Scale (DS14), Patient Health Questionnaire (PHQ-9).

Figure 2

Systematic Review: Search and Analysls of Articles using Prisma Guidelines



Part C: Manuscript Two:

Concept Analysis of Social Facilitation: Uncertainty in Living with an ICD

Abstract

Introduction: Individuals living with an ICD may benefit from social support to improve their adjustment to living with the ICD. Social facilitation, defined using Zajonc's (1965) Drive Theory, identifies the influence of presence to arouse and influence performance. This concept analysis of social facilitation aimed to clarify the influence on uncertainty of living with an implantable cardioverter defibrillator (ICD).

Method: Clarification of the concept of social facilitation regarding the adjustment to an ICD using the evolutionary method of concept analysis.

Results: Attributes identified included presence, influence, and collaboration. Antecedents include stability of social influence, emotional responses, sustained supportive relationships, and optimism. Engaging presence buffers potential negative consequences of going through complex situations.

Discussion: Much of the data on social facilitation relevant to psychology can be borrowed and applied to the care of individuals living with an ICD. Having a stable underlying condition, supportive relationships, and optimism improves social facilitation. In contrast, ICD shocks, instability of relationships, and fear increase stress and anxiety and degrade social facilitation**.**

Conclusion: Integrating the concept of social facilitation into a holistic care model assists patients in adjusting to a complex health issue. Social facilitation is improved when presence elicits positive, collaborative support for the psychosocial needs of those living with an ICD.

Key Words: social facilitation, psychology, implantable cardioverter defibrillator, living with, uncertainty

Highlights

- The concept analysis of social facilitation applies to adjustment to an ICD.
- Three attributes of the concept of social facilitation were defined: presence, influence, and collaboration.
- Nursing can borrow much of the data on social facilitation from psychology for application in the care of individuals with an ICD.
- The attributes of the concept of social facilitation can be applied to the care of individuals with an ICD to enhance the identification of psychosocial needs and care delivery.

Background

The desire to improve the knowledge and care of complex conditions prompted multiple healthcare disciplines to incorporate the concept of social facilitation into their theoretical frameworks for conducting research (Grey et al., 2006; Ryan & Sawin, 2009). Social support can act as a protective defense for individuals living with complex health conditions. A complex health condition, cardiovascular disease (CVD), can create uncertainty and stress for individuals (Heidenreich et al., 2011). Treatments for CVD include using an implantable cardioverter defibrillator (ICD) to prevent sudden cardiac arrest (SCA) for those at risk. An ICD is a device designed to detect and treat life-threatening arrhythmias; therefore, living with an ICD can create uncertainty related to condition severity, imposed stress, and lack of acceptance of technology. Individuals living with an ICD may benefit from social support as they can improve their adjustment to living with the ICD. Clarification on how social networks facilitate individuals with adjustment to complex and stressful interventions such as an ICD is needed.

Rogers's Evolutionary Method

Roger's evolutionary method of concept analysis is a systematic approach to concept analysis that provides a means to define and examine complex concepts such as social facilitation (Meleis, 2018; Rodgers & Knafl, 2000). According to Rodgers, concepts are formed iteratively by identifying characteristics influenced by social interaction and can vary depending on the specific setting. Identifying significant attributes applicable within a situation or circumstance further defines the concept (Rodgers & Knafl, 2000). The concept analysis steps for social facilitation, related to adjusting to living with an ICD, are highlighted in Table 2.6.

Table 2.6

Evolutionary Method of Concept Analysis: Social Facilitation and Living with an ICD

1. Identify concept of interest and associated terms	Historical perspective of concept of social facilitation provides baseline; aim to expand in relation to ICD Key terms: Social facilitation or social network or social support, implantable cardioverter defibrillator
2. Determine setting and sample for data collection	Databases: CINAHL, Psych Info, Pub Med, Google Scholar
3. Collect and manage data; identify attributes, antecedents, and consequences	Inclusion criteria: peer reviewed; English language articles published from 2010 to 2021 relevant to concept analysis of social facilitation related to uncertainty living with an ICD
4. Analyze data	Review of abstracts addressing key terms
5. Identify exemplar if appropriate	Identified key experiences related to the aim
6. Interpret results and implications; further development of concept	Results: attributes, antecedents, consequences identified Discussion of implications of social facilitation on adjustment to living with an ICD

(Rodgers & Knafl, 2000)

Identification of the Concept and Associated Terms

Integrating the concept of social facilitation into a holistic care model assists patients in adjusting to a complex health issue. Identifying relevant definitions for the concept is a part of discovery and induction within the evolutionary method (Rodger & Knafl, 2000). Current definitions of social facilitation confirm that earlier psychological descriptions remain valid and provide a framing of the concept related to living with an ICD. This paper aims to explore how healthcare professionals can implement social facilitation to manage an individual's uncertainty when adjusting to living with an ICD.

Historical Perspective

A foundation of the concept was laid from a historical perspective. Historical information on the concept of social facilitation, including current definitions, provides a foundation for understanding factors impacting care for individuals living with an ICD. Identifying past and current uses of the concept of social facilitation provides an understanding of the historical context (Rodgers & Knafl, 2000).

Social facilitation is not a new concept and has a long history in psychology for influencing the completion of tasks. The concept of social facilitation was examined and incorporated within psychology by Triplett in 1898. Triplett discovered that social presence influenced the performance of cyclists racing one another, which became the metaphor for social facilitation. Allport (1920) expanded the concept of social facilitation, including the co-action, or psychological influence, of individuals working in the presence of one another. Dashiell (1930) found that having an audience evaluate one's performance can limit or change an individual's behavior or social facilitation. Reportedly, an individual's relationship with their audience, including their attitude, co-action, or evaluation, affects their performance (Aiello & Douthitt,

2001; Dashiell, 1930). Zajonc (1965) defined *social facilitation* as a response to stressful or fearful experiences that elicit an arousal response. During familiar, more straightforward tasks, the “presence of others” elicits high arousal and improves the performance of individuals engaged in a task. In contrast, the “presence of others” when an individual performs a complex task, can elicit abnormal arousal and cognitive overload, increasing stress and anxiety and diminishing performance (Zajonc, 1965; Zajonc, 1980). Zajonc's Drive Theory remains the most commonly used and accepted social facilitation theory in psychology research today (Aeillo & Douthitt, 2001; Claypoole & Szalma, 2017). Shiffrin and Schneider (1977) expand on how tasks are managed, with simple tasks automatically being processed, which enhances an individual's performance, though cognitively complex tasks can be distracting. Baron et al. (1978) notes that close social networks (e.g., spouse) can distract individuals from completing primary tasks, creating a conflict in the focus and attention required to move on to a secondary task. Bond (1982) described how presence influences an individual's performance by empowering them to perform simple tasks, which can be deflating during complex tasks. Social facilitation is a concept that evolved to include an individual's self-awareness, reactivity to experiences, perceptions, and personality. Individuals' varying influences of physical or emotional presence and the power of social networks expanded the concept of social facilitation outside of psychology and into business, marketing, and healthcare (Aiello & Douthitt, 2001). This analysis included definitions of social facilitation in science, psychology, and general dictionary sources (Table 2.7).

Table 2.7

Social Facilitation Definitions related to Living with an ICD

Concept	Definition	Source
Social Facilitation	"Intensification (i.e. facilitation) of a behavior (e.g. feeding) that is associated with increased population density"	(Oxford University Press, 2022)
	"when we improve our performance in a task when other people are present. This could be due to a heightened state of awareness. Some people in contrast perform worse. See audience effect."	(Psychology Dictionary.org, 2022)
Social	(1) "involving allies or confederates," (2) "marked by or passed in pleasant companionship with friends or associates," (3) "of or relating to human society, the interaction of the individual and the group, or the welfare of human beings as members of society," (4) "tending to form cooperative and interdependent relationships with others," (5) "of, relating to, or based on rank or status in a particular society,"and (6) "being such in social situations."	(Merriam-Webster Dictionary, 2022)
Facilitation	"act" or a "state of being" within the context of "the increasing of the ease or intensity of a response by repeated stimulation"	(Merriam-Webster Dictionary, 2022)
Audience Effect	"the influence of the presence of other people on an individual's behavior. Also refers to the belief that other people may subsequently learn of the behavior. Performance is often improved when the action is simple and well-learned, for example in a factory, but may be inhibited when an action is complicated, difficult to perform, or when the person believes the behavior might incur the audience's disapproval."	(Psychology Dictionary.org, 2022)
Live With (something)	"To accept or come to terms with something, especially that which is disappointing, undesirable, or upsetting." "To put up with, accept, tolerate."	(Farlex Dictionary of Idioms, 2022; Merriam-Webster Dictionary, 2022)

Associated Terms Related to Living with an ICD

Within the healthcare arena, healthcare providers use social facilitation to assist patients in completing care routines. Clarifying the concept of social facilitation required a literature search on managing an individual's uncertainty when adjusting to living with an ICD. The literature search included social facilitation, social network, and social support concepts. Healthcare literature has used the concepts interchangeably to address the social impact of living with an ICD.

Determining Setting and Sample for Data Collection

The use of social facilitation examined in the literature included applying keywords to identify common themes: "social facilitation," "social network," "social support," and "implantable cardioverter defibrillator." The search was limited to 11 years, from 2010 to 2021, to remain current and relevant. The search included the following databases: CINHAL, PubMed, Psych Info, and Google Scholar. PRISMA guidelines yielded 23 articles analyzed for data contributing to clarifying the concept (Table 2.8).

Table 2.8

Social Facilitation Attributes: Data related to Living with an ICD

Author/Year Discipline/Journal	**Source of Presence**	**Type of Influence**	**Impact of Collaboration**
Allemann et al., 2018 Nursing *Journal of Cardio-vascular Nursing*	Partner	Lower amount of support: -lower perceived control -isolation or living alone -greater effect on women Greater support buffers: -lack of control in life -depression or anxiety -control over condition	Partner support affects: -quality of life -depression symptoms -perception of health status -control over daily life Lower perceptions of support: -ICD shock -more comorbidities -more symptoms of depression -worsened health condition Complex relationship between perceived partner support and psychological well-being and control over condition
Dehghanzadeh et al., 2017 Nursing Medicine *Nursing & Health Sciences*	Partner Healthcare Team	Seek versus isolate from support related to psychological challenges	Loss of social networks from job Loss or role change impact feelings of control Partner overprotection hinders adjustment Healthcare team emphasize tangible support over psychosocial support
Flannagan et al., 2010 Nursing *MEDSURG Nursing*	Partner Healthcare Team Community	Varied positive or negative influence	Alleviate overprotection or micro-managing of partners by: -seeking support from strangers -focus on keeping self-routines -isolating from partner Healthcare team has positive impact if authentic, present, and caring
Flemme et al., 2011 Nursing *Journal of Clinical Nursing*	Partner Healthcare Team	Isolation, evasion of social networks related to depression and pessimism Healthcare teams provide supportive knowledge and emotion regulation	Healthcare team supportive communication -decreases anxiety -increases perceptions of control -increases quality of life Seek healthcare team support for managing condition, ICD treatment, or psychosocial concerns
Fluur et al., 2013 Nursing Medicine *Journal of Advanced Nursing*	Partner Family	Varied based on role changes of individual, partner, and family	Role changes affect levels of: -feelings of control over daily living -feelings of isolation vs intimacy -experiences and optimism -vigilance or overprotection -knowledge sought

Friedmann et al., 2014 Nursing *Journal of Cardio-vasular Nursing*	General Social Support	Support groups offset effects of psychological distress Influences level of depression when heart failure present	With heart failure comorbidity -social support reduces depression -requires social support to offset if poor self -managing of condition -support has no effect on anxiety Support groups improve health behaviors and psychological status
Hammash et al., 2018 Nursing Medicine Psychology *Australian Critical Care*	Partner Family Healthcare Team	Lower support correlates with lower perception of control	Psychoeducational support improves perception of control over giving knowledge Health related quality of life (HRQOL) is related to: -engaging in social activities to support daily living -having fulfilling relationships
Hill et al., 2014 Nursing Social Care *BMJ*	Healthcare Team	Varied influence on of lack of knowledge and uncertainty; Emotional support influences response to topics such as end of life	Healthcare team delivery of tangible knowledge support affects complex care and decision making
Humphreys et al., 2015 Psychology Public Health *Heart & Lung*	Partner Healthcare Team	Lack of intimacy promotes isolation and emotional instability	Healthcare team psychosocial educational support: -reduces anxiety and depression -improves adjustment Isolate from social network to: -prevent overprotection -prevent worrying by partner protect family well-being
Knoepke & Matlock, 2017 Medicine Social Work *National Association of Social Workers*	Healthcare Team Community	Support in form of knowledge influences understanding and adjustment	Healthcare team support for providing knowledge in form of paper information, online references, or support groups Complexity of condition often requires need for more tangible knowledge support
Morken et al., 2014 Nursing Medicine Health Studies *Journal Advanced Nursing*	Healthcare Team	Varied effects of psychosocial and knowledge support Constructive support has positive influence and non-constructive support has negative influence on acceptance, anxiety, or ICD shocks	Build relationships by: -time with individuals -giving supportive knowledge -effective communication Tangible knowledge and psychosocial support: -constructive support promotes optimism and acceptanc

Murry et al., 2021 Psychology *BMC*	Healthcare Team Community	Varied with psychosocial distress	Healthcare team provides holistic support. Support groups utilized to address: -psychological effects -role changes and daily functioning -self-managing condition -ICD functions and shocks -identifying roles and relationships
Ooi et al., 2018 Nursing *Heart & Lung Journal*	Partner Family Healthcare Team Community	Tangible knowledge support, optimism, and empathy have positive effects Partners main influence on day-to-day living. Family and friends are emotional and social support. Healthcare team trusted knowledge and advocacy. Community religious and emotional support to reduce stress.	Effects of support on adjustment Protectiveness has varied influence - Lack of intimacy hindering and promotes isolation -Fear-based dependence on social support hinders self-directed social activity and interaction -Improved with family support -Improved by empathy -Lack of constructive support from healthcare team increases insecurity, psychological distress, and reduces device acceptance -From similar demographics and experiences facilitates adjustment
Palacios-Ceña , Losa-Iglesias, et al., 2011 Nursing Psychology Physical Therapy *Geriatrics Gerontology International*	Partner Family Healthcare Team	Optimism influences feeling of control. Partner or Family support influences positive outlook and feeling safe. Fear of death and abandoning partners or family influences health. Healthcare team knowledge is trusted.	Improved adjustment from support: - Keeping routines Feeling of protection effects collaboration with support: -Keep information from on shocks, symptoms, psychological concerns, and changes in condition from support networks to reduce worry, non-acceptance of physical condition, or overprotection. -Loss of roles impacts independence, social status, and relationships
Pedersen et al., 2010 Medicine Psychology *Europace*	General support	General social support is protective	Support improves adjusting to psychological distress or comorbidities. Tangible knowledge support along with rehabilitation or psychosocial programs is protective for anxiety.
Pedersen et al., 2017 Medicine Psychology *Europace*	Healthcare Team	Supportive knowledge on condition and emotional support for psychological concerns. Value of a supportive relationship and access to healthcare team.	Tangible and emotional support for illness and daily living improves biopsychosocial outcomes. Requests to promote adjustment: -Ongoing psychological support -Individual and family care options -Repeated knowledge over time -Support for daily living -Group workshops

			-In-person follow-up -Monitored exercise program
Rottmann et al., 2018 Medicine Psychology Public Health *Journal of Psycho-somatic Research*	Partners General social support	Positive influence after ICD shock on psychological distress and feeling of helplessness	Social support indirectly improves adjustment by decreasing anxiety and depression. Lower collaboration with support: -more vulnerable to distress -higher disease burden with shocks, secondary prevention indication, and heart failure
Sert et al., 2020 Nursing *Journal of Advanced Nursing*	General social support	Alleviates feeling of restriction to daily and social life and feeling of dependence	Seek out support groups when: -Increased restrictions on daily living, feeling dependent, or fear of shocks -Emotional support and monitoring needed to reduce uncertainty.
Srivatsa et al., 2020 Medicine *Critical Pathways in Cardiology*	Healthcare Team	Supportive tangible knowledge and emotional support	Support in-person, rather than by remote, perceived as facilitating opportunity for social support and asking questions
Srivatsa et al., 2020 Medicine Psychology *PACE*	Healthcare Team	Tangible knowledge support affects acceptance and psychosocial needs	Shock anxiety and device acceptance improved with: -Tangible knowledge support -Group social support
Wilson et al., 2013 Nursing Psychology *Journal of Cardio-vascular Nursing*	Healthcare Team Community	Tangible knowledge and psychosocial support influence acceptance	Support that improves psychosocial adjustment and acceptance: -Knowledge -Support groups -Cognitive behavior therapy -Physical exercise training
Wising et al., 2021 Nursing Medicine Social Work *European Journal of Cardio-vascular Nursing*	Partner Healthcare Team	Healthcare team trusted for supportive knowledge Healthcare team language of delivery vital to influence	Partners have supportive roles in medical management. Healthcare Team knowledge and emotional support. -Varies with condition complexity trajectory of illness, or shocks -Support can build gratitude for ICD, trust, feeling of safety and positively affect well-being

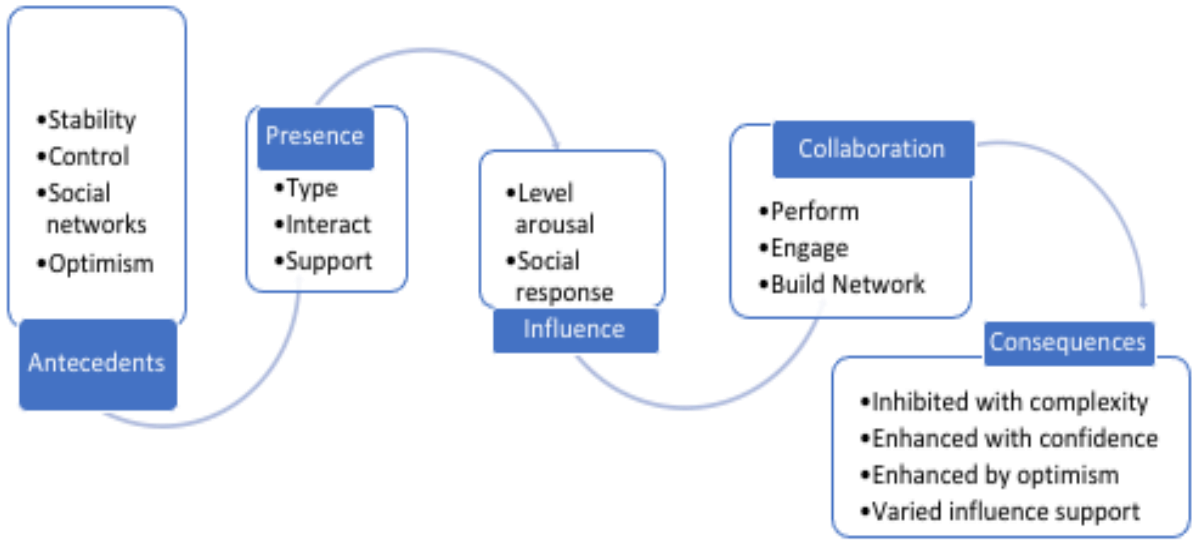
Identify Attributes, Antecedents, and Consequences

Attributes

Social facilitation occurs when cooperative and interdependent relationships with others form to ease an individual's anxiety as they adjust to living with the ICD (Oxford Reference, 2017; Psychology Dictionary.org, 2022; Merriam-Webster Dictionary, 2017; Farlex Dictionary of Idioms, 2015). The attributes of presence, influence, and collaboration were reported in the literature as necessary for improving social facilitation (Figure 3).

Figure 3

Model for Analysis of Social Facilitation



Antecedents

Antecedents are the processes required for social facilitation (Rodgers & Knafl, 2000). Successful facilitation occurs when the individual living with an ICD has stable influences from sustained social relationships and control over their lives based on prior experiences and demonstrates an optimistic outlook. Effective social support from families, health professionals,

and community resources is foundational to the social facilitation of living with an ICD. Stable relationships that provide positive influence can influence the adjustment to living with an ICD. Partner and family relationships, experiences with healthcare professionals, and past ICD treatment influence an individual's feelings of control over living with an ICD. An unstable condition, social network, or role change may lead individuals with an ICD to feel like they have less control over their life and the potential for a diminished adjustment. The sustained presence of supportive social networks improves the facilitation of adjustment to situations that occur while living with the ICD over time.

Consequences

Social facilitation occurs more readily during simple experiences with an ICD. Simple experiences enhance a normal response, including an implant for primary prevention; a stable underlying condition; the absence of ICD shocks; and supportive, optimistic social relationships. In contrast, social facilitation is less likely to occur in difficult or complex experiences when individuals have an ICD implanted for secondary prevention; have a complex underlying condition with multiple comorbidities; are experiencing pessimism, fear, anxiety, or stress; and do not have supportive relationships. An individual's adjustment to the complexity of living with an ICD can be buffered by engagement with a supportive, trustworthy social network that encourages confidence and optimism. Conversely, the individual's social network diminishes the facilitation of adjustment when they are negatively focused, doubtful, or do not promote confidence.

Data Analysis and Interpretation of Results

Presence

Social presence, a foundational attribute of social facilitation, may influence an individual's performance of tasks or adjustment to situations (Triplett, 1898: Zajonc, 1965). An individual's response to situations can be altered by the actual, potential, or assumed presence of others. Presence can heighten an individual's awareness or alertness to circumstances and surroundings and elicit arousal to action (Bond & Titus, 1983; Claypool & Szalma, 2017). The presence of partners, family members, healthcare professionals, and community members may impact the response of individuals living with an ICD (Table 2). Presence of partners is more intimate and constant in daily life than the presence of other supports that individuals with an ICD might receive. A partner's emotional physical, and relational values and health status are varied and may or may not align with those of individuals living with an ICD. Identifying attitudes, co-action, or evaluation of social networks on individuals is essential to understanding the influence of their presence. Individuals living with an ICD and their spouse or family have roles as caregivers, leaders, and decision-makers; these roles assist in balancing the relationships and needs of the family unit. Individuals expect healthcare professionals to be both empathetic and up to date on the state of the science. Interactions with their community offer more remote support for individuals living with an ICD, whether at work, places of worship, schools, or gatherings (Flannagan et al., 2010; Ooi et al., 2018).

Severity of the condition of the individual living with an ICD influences the degree of social facilitation in which that individual participates. The complexity of the comorbidities or ICD shocks exacerbates the condition of the individual living with an ICD and increases their rejection of the presence of others. An individual's condition complexity or role adjustment

impacts their relationships with family and friends, and their social network can shift from supportive to burdensome. The presence of healthcare professionals as trusted experts can also strengthen an individual living with an ICD's social facilitation through tangible support in the form of knowledge and advocacy (Dehghanzadeh et al., 2017; Flemme et al., 2011; Hill et al., 2014; Ooi, 2018). Community support groups providing professional and non-judgmental support mixed with warmth can strengthen an individual's social facilitation by providing spiritual and emotional support to reduce stress.

Influence

The influence of social presence on adjustment to living with an ICD depends on the relationship with the individual living with an ICD and the impact of their engagement (Claypool & Szalma, 2017). The factors influencing the impact of social presence of others on individuals living with an ICD include the height of arousal (how much the individual is affected by the presence), level of social capital (how extensive and influential their social network is), and level of evaluation (whether they evaluate how the individual is adjusting). Individuals with more significant influences of power, such as supervisors, health professionals, significant others, family, or friends, can influence adjustment (Bond & Titus, 1983). The degree of influence of presence relates to how much the relationship affects daily living with the ICD, such as a change in roles or feelings of security (Bond & Titus, 1983; Fluur et al., 2013). A significant change in the life of the individual living with an ICD, such as a job loss or a change in health condition, may diminish feelings of optimism, safety, and security (Fluur et al., 2013). Significant other and family presence can strengthen feelings of optimism, safety, and security for those with the ICD if they do not fear the loss or death of their loved one (Palacios-Ceña, Losa-Iglesias et al., 2011). Partners are the affected individuals' primary influence on the experience of living with an ICD.

An individual's adjustment to living with an ICD may be improved if their partner's presence is supportive, nurturing, empathetic, and not overbearing (Ooi, 2018). Partners can be a positive buffer for the emotional reactions of the individual living with an ICD (Allemann et al., 2018; Dehghanzadeh et al., 2017; Flannagan et al., 2010). Although family and friends can influence an individual's adjustment to living with an ICD, they often take a lesser role than partners in influencing emotional and physical adjustment (Ooi et al., 2018).

The supportive presence of others can protect those living with an ICD, buffering feelings of depression or anxiety and perceptions of control or lack of control over the condition. Positive or negative experiences with social presence can improve or deflate an individual's confidence to adjust to living with an ICD. An individual with a positive perception may have higher self-esteem and show improved adjustment when pressured socially; however, an individual with a negative perception may have lowered self-esteem and struggle with adjustment (Uziel, 2007). The variable influence of social presence may impact the individual living with an ICD's ability to adjust their behavior or adapt effectively during psychosocial challenges (Ryan et al, 2011; Sawin et al., 2017).

The presence of healthcare professionals as trusted experts can also strengthen an individual living with an ICD’s social facilitation through tangible support in the form of knowledge and advocacy (Dehghanzadeh et al., 2017; Flemme et al., 2011; Hill et al., 2014; Ooi et al., 2018). Individuals living with an ICD often seek knowledge from health providers but may not understand or be receptive to the information they receive (Allemann et al., 2018; Dehghanzadeh et al., 2017: Hammash et al., 2018; Hill et al., 2014; Pedersen et al., 2010; Sert et al., 2020; Srivatsa et al., 2020; Wilson et al., 2013). Knowledgeable and trusted health professionals can positively influence an individual’s adjustment to living with an ICD

(Dehghanzadeh et al., 2017; Fleme al., 2011; Hill et al., 2014; Wising et al., 2021). Community support groups providing professional and non-judgmental support mixed with warmth can strengthen an individual's social facilitation by providing spiritual and emotional support to reduce stress. Health professionals have a more impactful influence on addressing individuals' adjustments to living with an ICD if they are flexible with the strategies, they implement along the illness trajectory. The ongoing strain of comorbidities, such as heart failure or ICD shocks, can negatively impact the psychosocial adjustment of individuals living with an ICD; however, the supportive presence of partners and general supports can potentially reduce feelings of distress or helplessness (Friedmann et al., 2014; Rottmann et al., 2018).

Collaboration

Presence requires collaboration between individuals living with an ICD and their social sphere of influence. The social sphere of influence is established based on the proximity and role of each social relationship in the life of the individual living with an ICD. Enhanced social facilitation requires a significant other's presence be a positive and interactive. Relationships that are cooperative, optimistic, and trusting improve confidence and facilitate the adjustment.

Effects of Collaborative Support

Collaborative support and relationships that encourage psychosocial adjustment and acceptance also facilitate buffering of psychological distress for individuals living with an ICD (Allemann et al., 2018; Dehghanzadeh et al., 2017; Friedmann et al., 2014; Hammash et al., 2018; Humphreys et al., 2015; Wilson et al., 2013). Individuals living with an ICD who receive knowledge-based psychosocial support engage in physical and social activities that develop fulfilling and supportive relationships, improving their health-related quality of life (HRQOL) (Hammash et al., 2018). However, building a supportive relationship takes time, and support

networks for individuals living with an ICD can have varied impacts on their daily lives. Constructive support promotes optimism, whereas unsupportive relationships can promote fear and insecurity. Collaboration with others can strengthen a person's adjustment to living with an ICD when relationships support empowerment through optimism, supportive endeavors, intimacy, and the building of knowledge and feeling of control over the environment (Fluur et al., 2013; Morken et al., 2014; Ooi et al., 2018).

Co-managing with Others

A complex relationship exists between an individual and their significant others or family members who co-manage living with an ICD. Significant others and family may have supportive roles in building positive well-being for those living with an ICD through interactions of gratitude, trust, and safety. Effective social presence from significant others and family projects empathetic support that is collaborative with the wants and needs of the individual living with an ICD. The perception of protection promotes feelings of collaboration with a supportive presence. Overprotection between the individual living with an ICD and their significant other is an example of ineffective collaboration with a person, resulting in isolation and loss of intimacy. Some individuals living with an ICD avoid collaborating with their family to protect their family's emotional well-being (Allemann et al., 2018; Dehghanzadeh et al., 2017; Flannagan et al., 2010; Humphreys et al., 2015; Wising et al., 2021). To alleviate the loss of intimacy induced by overprotection, individuals living with an ICD often seek support from strangers in the form of support groups in similar situations (Flannagan et al., 2010; Humphreys et al., 2015; Palacios-Ceña, Losa-Iglesias et al., 2011).

A holistic form of care provides for the biopsychosocial needs of individuals through tangible support, including knowledge and emotional support, to adjust to living with daily

concerns related to condition, treatments, and illness (Dehghanzadeh et al., 2017; Knoepke & Matlock, 2017; Pedersen et al., 2017). Healthcare professionals can provide holistic support to positively impact the adjustment to living with an ICD by being authentic, empathetic, and engaged. Individuals living with an ICD seek professional support from healthcare professionals related to their condition, helo understanding the ICD, or assistance with their psychosocial concerns (Flannagan et al., 2010; Flemme et al., 2011; Morken et al., 2010). Healthcare professionals primarily offer tangible support, such as providing education on the ICD and physically adjusting to living with an ICD, over psychosocial support. Individuals with an ICD request ongoing psychological support, individual and family care options, multiple reviews of the need for knowledge over time, support for daily living, group workshops, in-person follow up, and exercise monitoring to improve adjustment (Pedersen et al., 2017). Group support that provides knowledge of ICD and social support can lessen shock anxiety and increase device acceptance (Srivatsa et al., 2020).

Supportive, collaborative community presence enables individuals living with an ICD to maintain routines and interactions in their places of work and play. Interactions with community support groups of similar demographics and experiences can provide a valuable forum to address everyday life's psychological, physical, and relational changes from living with an ICD (Flannagan et al., 2010; Murry et al., 2021; Ooi et al., 2018).

Psychosocial Perceptions of Health Condition

An increase in the complexity of a condition requires an adjustment to the illness trajectory and can impact how individuals collaborate with others. Individuals living with an ICD perceive they receive less support when their condition is severe, or they are dependent on others. Those individuals may seek communication, knowledge, and emotional support from

community groups when they have restrictions to daily living, are dependent, or fear shocks. Interaction with community support groups and monitoring from health professionals reduces uncertainty (Sert et al., 2020). Support can improve individual's reactions to living with an ICD or comorbidities when the support provides knowledge, rehabilitation, or psychosocial intervention. Individuals living with an ICD perceive non-constructive support as inadequate in fostering change, which can accentuate feelings of fear and insecurity (Morken et al., 2014; Ooi et al., 2018; Pedersen et al., 2010).

Identify an Exemplar

Alex, a wife, teacher, and mother of two, had an ICD implanted six months ago. She had adjusted to living with an ICD until she received a shock from her device. During the shock, Alex was alarmed that the sudden, painful jolt to her chest meant her ICD was not working. When Alex first received the news of her heart condition, she had been alarmed at the recommendation for an ICD implant to protect her from the risk of SCA. The suddenness and newness of the experience of a shock from the device left Alex feeling vulnerable and uncertain. Her thoughts turned to her family and the fear of dying as Alex thought about how her death would impact the lives of her children and husband. Remembering the instructions their healthcare team gave them in the event a shock occurred, her husband called 911 (presence, influence, collaboration). The healthcare team was ready when Alex arrived at the hospital (presence) and helped her to understand why she was experiencing the shocks (influence). Alex received a new plan of care from her healthcare team with medications, a three-month driving restriction post-shock, and an outpatient follow-up schedule (collaboration). The team supported Alex as she healed by providing relaxation and stress relief techniques and addressed her psychosocial concerns with living with the ICD (collaboration). Alex expressed her thankfulness

for the expert knowledge and compassion (influence) she received from her healthcare team (presence). The plan of care provided Alex with reassurance that she would be able to resume her daily routine (collaboration). At home, Alex's family and friends rallied around her, caring for her children, cooking, cleaning, and providing transportation (presence, influence, collaboration). Alex's trusted support team helped her remain optimistic during this stressful time (presence, influence).

Discussion: Implication of Social Facilitation on Living with an ICD

The concept of social facilitation has been incorporated into theoretical frameworks in psychology and nursing. Variations in social facilitation occur based on the situational, sociocultural, and disciplinary settings in which individuals receive care. In psychology, social facilitation theoretically and practically influences behavior modification, behavior analysis, and decision-making (Ahmad, 2016; Baxter et al., 1990; Claypool & Szalma, 2017; Schweizer et al., 2014). Social facilitation is identified in nursing as an essential part of theoretical frameworks to guide practice which influences behavior modification and self-management of chronic conditions across age groups (Bonis & Sawin, 2016; Yun & Kim, 2017; Ryan et al., 2011; Ryan & Sawin, 2009; Sawin et al., 2017). Nursing and psychology utilize different approaches in the conceptualization of social facilitation. The concept of social facilitation has been used in psychology to assess the impact of peer pressure on smoking (Schweizer et al., 2014), whereas several studies in nursing focus on the influence of social facilitation on the self-management of complex chronic conditions (Yun & Kim, 2017; Ryan & Sawin, 2017).

Social facilitation occurs when the individual's social networks are a trusted, empathetic, and collaborative part of their health journey. Navigating complex experiences can be buffered through supportive measures that provide the emotional and physical needs of individuals living

with an ICD. The severity of an underlying condition can elicit heightened feelings of stress and cognitive overload for those living with an ICD, especially when a higher risk of mortality is evident. Relationship dynamics can help or hinder social facilitation in situations where an individual living with an ICD has heightened reactions to their circumstances. Examples of relationships that help social facilitation of care include relationships with partners, family, health providers, and the community that bring a sense of calm and order to the situation. Examples of relationships hindering social facilitation include spousal stress, limited time with health professionals, and feeling devalued at the workplace. Social networks also influence adjustment to the ICD in everyday life and the individual's roles at home, work, and healthcare. Identifying psychological reactions to presence may lead to more successful collaborative interventions to improve adjustment to living with an ICD (Ryan et al., 2011; Uziel, 2007).

A feeling of stress can occur from the presence of another person depending on the influence of the social network involved, the response of the individual living with an ICD, or their acceptance of assistance. Constructive support from others positively influences acceptance of the device, anxiety, or experiences with living with the ICD (Flannagan et al., 2010; Morken et al., 2014; Ooi et al., 2018). Stress can reduce the effects of social presence on emotional regulation and acceptance of the ICD, especially with sensitive topics such as the end of life (Flemme et al., 2011; Hill et al., 2014; Pedersen et al., 2017). Individuals living with an ICD may be more stressed from the presence of others when the presence increases anxiety or exacerbates loss of control over daily living (Ahmad et al., 2016; Bonis & Sawin, 2016; Claypool & Szalma; Yun & Kim, 2017). Women who feel less supported and individuals who live alone often lack the stabilizing intimacy of others to remain emotionally regulated while adjusting to living with an ICD (Allemann et al., 2018; Humphreys et al., 2015). Although individuals may isolate

themselves from others to prevent embarrassment or overt emotional reactions when situations occur, this may have the opposite intended outcome and lead to depression (Dehghanzadeh et al., 2017; Flemme et al., 2011). Support that promotes optimism positively affects psychological distress and feelings of control, whereas pessimism can lead to defeatism and depression (Flemme et al., 2011; Murry et al., 2021; Ooi et al., 2018; Palacios-Ceña , Losa-Iglesias, et al., 2011).

Conclusion

Integrating the concept of social facilitation into a holistic care model assists patients in adjusting to a complex health issue. Social presence can either facilitate adjustment or promote self-isolation and maladjustment. Varied responses occur for those living with an ICD during engagement with their social networks. Individuals requiring an ICD implant for primary prevention of a SCA who have an optimistic outlook and supportive relationships have reported less stress and greater acceptance. Conversely, individuals with an ICD experiencing shocks, dysfunctional relationships, or fear, are prone to increased stress and decreased adjustment. The positive presence of others can elicit collaborative support for the psychological and physical needs of those living with an ICD. Therefore, healthcare professionals should encourage social networks for individuals living with an ICD to assist them in managing uncertainty and facilitate adjustment.

Chapter Summary

Chapter two provides an overview of what an ICD is, why individuals may receive an ICD and the impact of the ICD on their lives. The findings from the literature support the need for a study on the psychosocial perceptions of individuals living with an ICD based on identified gaps. The manuscripts in this chapter provide supportive literature on the need to address the psychosocial aspects of living with an ICD. A systematic review of the literature provides information on the potential trauma individuals living with an ICD face and the need to address psychosocial factors that affect adjustment to living with the ICD. The concept analysis of social facilitation provides evidence of the potential impact of social networks individuals living with an ICD engage in their daily lives. The results of this study could provide information on the psychosocial factors that influence psychosocial well-being.

Chapter Three: Methodology

Psychosocial concerns are not routinely screened for in individuals living with an implantable cardioverter defibrillator (ICD). However, individuals living with an ICD can find it psychologically challenging or traumatic (Anudulv et al., 2012; Dougherty et al., 2012; Kremers et al., 2013; Ooi et al., 2016). When living with an ICD is traumatic for individuals, it can negatively impact their uncertainty and adjustment (Dougherty, 2019; Dunbar, 2005; Ford et al., 2013). Early screening for the psychosocial needs of individuals living with an ICD provides opportunities to promote positive perceptions and outcomes (Dougherty et al., 2012). Therefore, it is important to assess the potential impact of the ICD on individuals to promote well-being and limit uncertainty.

Design

A quantitative exploratory-descriptive design was utilized to compile data to identify associations between potential factors related to uncertainty influencing individual adjustment to an ICD and psychosocial well-being (Polit & Beck, 2018). The *Impact of Uncertainty on Psychosocial Well-Being* model (Figure 2) provides a framework for exploring the independent variables related to uncertainty in living with an ICD and the dependent variable of psychosocial well-being. Data was collected utilizing measurement instruments to answer the research questions and describe the associations among the variables.

Research Questions and Hypothesis

The purpose of this study is to examine how an individuals' perceptions of living with an ICD impacts their psychosocial well-being. Primary aims of this study are to examine the association between knowledge, severity of cardiovascular condition, individual stress appraisal, acceptance of ICD, and social facilitation with psychosocial well-being among adult participants

with an ICD. Descriptive research questions include (1) What is the cardiovascular condition for necessitating an ICD and knowledge level of an ICD among adult participants with an ICD?, (2) What is the individual stress appraisal among adult participants with an ICD?, (3) What is the acceptance level of an ICD among adults participants with an ICD?, (4) What is the level of social facilitation among adult participants with an ICD?, (5) What is the level of psychosocial well-being among adult participants with an ICD?, and (6) Controlling for age and sex, do knowledge of the ICD, severity of cardiovascular condition, individual stress appraisal, acceptance of the ICD, and social facilitation predict psychosocial well-being among adults with an ICD?

A hypothesis was identified for the main research question. Controlling for age and sex, knowledge of the ICD, severity of cardiovascular condition, individual stress appraisal, acceptance of the ICD, overall uncertainty, and social facilitation will predict psychosocial well-being in adults with an ICD.

Sample and Setting

A convenience sample was obtained from rural area clinics within a large medical center, other locations, and social media. Inclusion criteria for the study consist of (a) History of implantable cardioverter defibrillator (ICD) implant for primary or secondary prevention (post cardiac arrest or meeting of criteria for risk of SCA), (b) adults over the age of 18 years, (c) implant of ICD greater than 3 months, and (d) ability to speak, read and write in English. Exclusion criteria consist of (a) current hospitalization, (b) impaired cognition, and (c) international (Polit & Beck, 2017; Yamiz, 2013). Efforts were made to ensure the participants are demographically diverse, however, given the size of the sample, diversity was limited (Polit & Beck, 2017; Shadish, Cook, & Campbell, 2002).

Power Analysis

Sample size was determined through a power analysis. Power analysis is completed to assess the probability of detecting true relationships between variables and reducing the risk of Type I (alpha risk .05) or Type II (beta risk .80) errors. Type two errors occur if there is not a large enough sample to detect change when a change occurs. Power analysis is conducted to estimate sample size required to statistically analyze the data as accurately as possible, and require information on significance, sample size, effect size, and power (Polit & Beck, 2017; Hulley, et al., 2013). A power analysis was conducted with the help of a statistician to determine the sample size for this study. A priori power analysis was conducted with 80% power to detect a medium effect size ($\beta = 0.15$) with a .05 significance level with four independent variables (predictors) included in the model and using one outcome variable (well-being). Based on the analysis, a sample of 85 will be sufficient to address the research questions and inform the design of a larger study. An attrition rate of up to 10% is expected; therefore, 94 subjects were planned for recruitment.

Setting for Recruitment

Rural clinical sites within a large hospital system in a Midwestern city were the proposed setting of this study. The sites were chosen due to the active cardiac care that is provided to individuals with chronic cardiovascular conditions requiring an ICD. The ambulatory clinic provides services following implant of an ICD for ongoing evaluation and treatment. Healthcare providers at the site care for a population that is ethnically and economically diverse. The healthcare system is affiliated with a major metropolitan medical center. There is a commitment within the health system to innovation, compassion, service, dignity, and integrity to deliver quality care for clients. With the COVID-19 pandemic and social distancing orders limiting in-

person and on-site recruitment, recruitment was expanded to other individuals who may have contact with individuals living with an ICD including health professionals, social media, support groups, and word of mouth. A flyer describing the study was shared with potential sites via email or fax for recruitment of participants. A consent to communicate form was utilized to assist in referrals.

Recruitment

To reach the appropriate number of participants based on the power analysis, recruitment continued until an adequate number of participants were enrolled in the study (Polit & Beck, 2022). Recruitment strategies included flyers emailed and faxed to clinic settings, word of mouth from healthcare professionals, and snowball sampling. Flyers were distributed that included contact information for the researcher, purpose and length of the study, expectations for participants, and any potential benefit from participation. Administration of the survey was conducted via phone or zoom, based on participant preference, with guidance from the researcher. The researcher allowed participants the opportunity to ask questions. Patients were reminded that they did not have to answer any questions they did not wish to answer. Data was be compiled using Qualtrics software.

Data Collection

A 90-item survey was utilized to measure data for this investigation and explore the research questions. The survey was administered remotely via phone or zoom. Participant characteristics were compiled from each individual, including demographic and clinical information. The remaining survey included a compilation of the three measurement instruments that were utilized: the Florida Patient Acceptance Scale (FPAS), the Multi-dimensional Scale of Perceived Social Support (MSPSS), and the Psychological Well-being (PWB) scale. The survey

was formatted in Qualtrics format for accessible collection by the researcher reading the questions to the participants and direct entrance within the SPSS system for analysis.

Procedures for Collection of Data

Approval for the study was obtained through the IRB from the University of Wisconsin-Milwaukee. A secondary IRB approval was obtained from the University of Minnesota for recruitment at their clinic sites. Approval was be obtained prior to proceeding with the study and before any work or recruitment was initiated. Information was distributed using multiple recruitment strategies, including use of flyers, personnel contacts, and patient lists. Due to the COVID-19 pandemic, procedures were adjusted due to limitations of in-person participant access for recruitment, survey completion, and consent. Recruitment followed the identified strategies. Recruitment time was continued until the projected sample size was reached. This phase was anticipated to take 3 to 6 months but was longer due to unforeseen circumstances limiting access to participants. Participation in the study was voluntary. Participants were screened for meeting inclusion criteria and those interested in participation had the informed consent read to them for completion with verbal consent to participate in the study. Participants who completed the survey via the phone or zoom provided verbal and implied informed consent prior to the start of the survey. Once the screening and informed consent process was completed, each participant was provided instructions on how the survey would be conducted by phone or zoom. The participants were informed they may ask questions or decline participation at any time prior to completion of the survey, at which point the researcher would de-identify the data and would not be able to verify who the data came from. Participants were informed that choosing not to participate would not influence their relationship with their healthcare team or facility.

Procedures for Handling Data

The data collection was completed virtually or remotely. The survey was conducted using Qualtrics software, including all measurement instrument items and participant characteristic data. The survey was read to the participants by the researcher, and the researcher recorded their responses. Once data collection was completed, the data was transferred into SPSS using Qualtrics software for surveys. Data was reviewed for items missed by the researcher. Data was de-identified and stored on a password-protected computer to safeguard patient confidentiality. Only the researcher and necessary personnel for the completion of the research had access to the de-identified data, including the researcher's major professor, committee members, and biostatistician. To ensure accuracy, the researcher reviewed all data, and the data plan every ten patients to ensure the research plan was followed and data entry accuracy was confirmed. The researcher informed participants that de-identified data would be kept until the data could be disseminated or used for future research. Participants were informed that participation in the study should incur little or no risk. A $25 gift card was offered to participants to compensate for their time.

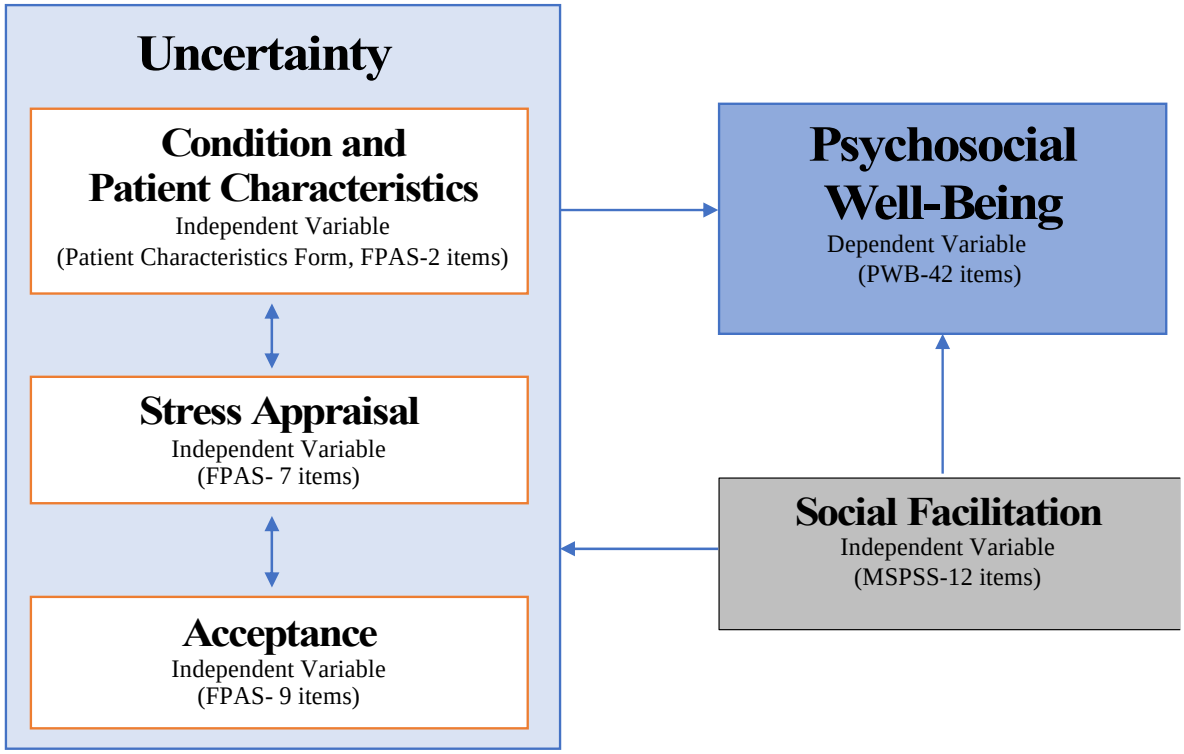
Variables

Four independent variables (IV) and one dependent variable (DV) were identified from the model and matched with measurement instruments that have been validated in studies on populations with chronic cardiovascular conditions or ICD (Figure 3). Condition and patient characteristics, stress appraisal, and acceptance were categorized under the umbrella of uncertainty to assess the impact of uncertainty on living with an ICD. An overview of the conceptual and operational characteristics of each variable is reviewed with justification for their use in this study. Each variable is illustrated to provide (a) context, (b) measurement instrument

and scoring method, and (c) reliability and validity scores (Table 3.1).

Figure 4

The Impact of Uncertainty on Psychosocial Well-Being Model with Instruments



Independent variables

The four IVs include condition and patient characteristics, stress appraisal, acceptance, and social facilitation. Condition and patient characteristics, stress appraisal, and acceptance are under the umbrella of uncertainty and were operationalized with different portions of the Florida Patient Acceptance Scale (FPAS). Therefore, a general overview of FPAS is included.

General Overview of FPAS

Description. Psychological factors affecting acceptance and adjustment to an ICD can be identified through screening with the FPAS (Versteeg et al., 2012). Because the FPAS is being used to measure several of the independent variables, a basic overview is provided here and

further expanded to pertinent material in the discussion for each specific variable. The FPAS is an 18-item instrument comprised of four subscales and three single-item questions that have been useful in multiple studies to examine acceptance of a cardiac implantable device, especially in those at risk for psychological issues (Burns et al., 2005; Versteeg et al., 2012). The four subscales of FPAS address various aspects of adjustment to living with an ICD. "Return to Life" addresses the individual's desire and ability to return to activities and patterns of life as before the ICD. The subscale of "Device-Related Distress" identifies whether stress related to living with an ICD is present. "Positive Appraisal of the ICD" identifies whether an individual has a positive attitude toward the ICD and has incorporated it as a necessary part of their new life. And lastly, "Body-image Concerns" addresses the potential impact of individual perceptions of how others view them based on having the ICD.

Items are measured using a 5-point Likert scale from 1 to 5, "strongly disagree" to "strongly agree," with higher scores indicating greater acceptance of the device. Fifteen items comprise four subscales including (a) "Return to Life," (b) "Device-Related Distress," (c) "Positive Appraisal," and (d) "Body Image Concerns." Three additional items are single questions to assess knowledge of the device and return to sexual activity. The time needed to administer the 18-item instrument was approximately 10 minutes (Burns, et al., 2005).

Reliability and Validity. Reliability measuring the Total FPAS demonstrated a Cronbach's alpha of 0.83, showing good internal consistency. Subscales also showed good reliability with Cronbach's alphas ranging from 0.74 to 0.89, which will be expanded on in discussion of each variable. Factor analysis of the FPAS and subscales confirmed the measurement instrument as valid for analysis of acceptance of an ICD. Psychometric analysis of the FPAS demonstrated validity when compared to five other self-report measures that covered

quality of life, and biological, psychological, and social components. Factor analysis suggested FPAS was dependable for measuring a comprehensive view of device-specific adjustment issues and interventions, with validity demonstrated across scales (Burns, et al., 2005). Factor analysis of a modified Dutch version of FPAS retained validity and reliability was seen across subscales with Cronbach alphas ranging from 0.76 to 0.82 (Versteeg et al., 2012). A study assessing racial and gender differences related to adjusting to an ICD retained reliability with a Total FPAS Cronbach's alpha of 0.85. Reliability across subscales also was retained with Cronbach alphas ranging from 0.77 to 0.88 (Wilson et al., 2013).

Scoring. To score the Total FPAS, the 15 items comprising the subscales are added together with care to reverse score nine of the items. The addition provides a total raw score which is subtracted by 15, the total number of items added. The result is then divided by 60 and then multiplied by 100 for a score (F-PAS Total score = 1® + 2® + 3® + 4® + 5 + 6 + 7 + 8 + 10 + 12® + 13+ 14® + 15® + 17® + 18® for raw score, then raw score -15/60 X 100; reverse score items marked ®). The three single items are scored individually. Higher scores for the Total FPAS are predictors of greater acceptance of the ICD (Burns, et al., 2005).

Condition and Patient Characteristics

Condition and patient characteristics are compiled to provide an overview of the patient social determinants of health (SDOH) and device-specific factors that may influence perceptions of the ICD. Condition and patient characteristics will be operationalized by responses to the patient characteristics form developed by the researcher (see Appendix B). The form comprised of 18 items with demographics (11) and device-(7) related questions to provide baseline patient characteristics and severity of condition. Questions on patient characteristics included age, gender, height and weight, marital status, ethnicity, religion, education level, annual household

income, comorbidities, smoking history, and social activities. Device-related items reported on implant year, complications, number of surgeries, reason for implant, work, driving, presence of shocks, and physical activity level. All questions were nominal, except age, height and weight, and education were ordinal. The self-report form will be filled out once to provide data for the researcher who will not have access to respondents' medical records. The researcher anticipates participants will need 10 minutes to fill out this portion of the survey. Mean and standard deviation (SD), and frequency will be used for scoring of age. Frequencies will be used on all other items.

Condition will also be operationalized by responses to two single items on knowledge from the FPAS not included in total scoring. The two single FPAS items identify (1) individual knowledge level of an ICD and how it works for them and (2) having enough knowledge about ICD (Burns et al., 2005). Wilson et al. (2013) utilized the 18-item FPAS; finding knowledge of device was one of the important factors related to greater acceptance. The two knowledge related items are not validated as part of a subscale and are scored individually. Higher scores on the knowledge items indicates better understanding of the ICD, how it works, and what it is intended to do for the individual (Burns et al., 2005).

Stress Appraisal

Description. Stress appraisal is conceptually defined by the impact the reaction to a life event may have on emotional stability and demands on an individual to change their lifestyle. Perceptions of demands of living with an ICD can trigger an emotional response that guides behavior and undermines a sense of stability (Lazarus & Folkman, 1984). Assessing the emotional representation of the ICD may reveal feelings of fear, anger, or distress that manifest as feelings of depression, inability to function, disfigurement, or avoidance (Lazarus & Folkman,

1984; Briere & Scott, 2015). Seven items from the FPAS will operationalize an individual's ability to return to physical and psychological function toward a pre-device state. The five-item "Device-Related Distress" subscale and two-item "Body Image Concerns" subscales measure perceptions of psychological instability and reduced ability to function after the ICD. Items address individual feelings of depression, avoidance, inability to function, or being unattractive (Burns et al., 2005).

Reliability and Validity. Reliability of the FPAS "Device-Related Distress" and FPAS "Body Image Concerns" subscales show good internal consistency with Cronbach alphas of 0.79 and 0.74 respectively (Burns, et al., 2005). Factor analysis confirmed that psychological distress was an important influencer of reduced acceptance (Pedersen, et al., 2008; Versteeg, et al., 2012).

Scoring. Of the seven items, none were reverse scored for subscale scoring. Scoring of the subscales starts with adding items within a subscale for a raw score. Final calculation is completed by taking the raw score and subtracting the number of items, dividing by 4 times the number of items, and multiplying by 100. Higher scores on the FPAS "Device-Related Distress" and FPAS "Body Image Concerns" subscales indicate the presence of psychosocial distress interfering with acceptance of the ICD. Therefore, the subsets are reverse scored for the FPAS "Total Score" to address the negative effects on total acceptance (Burns, et al., 2005).

Acceptance

Description. Conceptualization of acceptance related to uncertainty with living with an ICD relates to the ability to embrace technology and adopt a positive attitude toward the device. Therefore, acceptance occurs by engaging in a lifestyle that supports the physical and psychosocial aspects of living with the ICD (Dunbar et al., 2012). Nine items from the FPAS

will operationalize an individual's ability to return toward a pre-device state of physical and psychological function. The four-item FPAS "Return to Life" subscale and one-item FPAS "Return to Sex" subscale measure an individual's confidence to return to activities such as work, full life, family life, or physical activity. The four-item FPAS "Positive Appraisal" subscale measures perception of acceptance of an ICD as a safe, effective treatment option that individuals do not regret (Burns et al., 2005).

Reliability and Validity. Reliability of the FPAS "Return to Life" and the FPAS "Positive Appraisal" subscales show good internal consistency with Cronbach alphas of 0.89 and 0.82 respectively (Burns et al., 2005). In one study addressing the influence of gender and race on acceptance, reliability was retained with Cronbach alphas of 0.77 for FPAS "Return to Life" and 0.88 for FPAS "Positive Appraisal" suggests the value of using FPAS with diverse groups.

Scoring. Of the nine items, only two within the FPAS "Return to Life" subscale were reverse scored to obtain a subscale score, items 17 and 18. Scoring of the subscales for this variable starts with adding items within a subscale for a raw score. Final calculation is completed by taking the raw score and subtracting the number of items, dividing by 4 times the number of items, and multiplying by 100. The FPAS "Return to Sex Life" is individually scored and not validated as part of a subscale. Higher scores on the items 6 and 13 in the FPAS "Return to Life" subscale and the FPAS "Return to Sex Life" item predict the ability for the individual to reengage in life including physical and psychosocial activities. While higher scores on the reverse score items, 17 and 18, from the FPAS "Return to Life" subscale indicate a concern in their ability to participate with family or daily physical activities. Individuals who have higher FPAS "Positive Appraisal" subscale scores show positive acceptance of the ICD as a part of their treatment and life (Burns et al., 2005).

Social Facilitation

Description. Social Facilitation is conceptualized as the presence of support, the influence of support, and the degree of collaboration with supportive networks to promote change or adaptation to the ICD. Social support is included as a separate variable that may influence psychosocial well-being and will be assessed by the Multidimensional Scale of Perceived Social Support (MSPSS). Perceived support from family, friends, or significant others correlates with lower levels of depression and stress (Zimet et al., 1988). For this study, the presence of social support will be operationalized using the 12-item self-report MSPSS. The survey is measured on a 7-point Likert scale, with one being "very strongly disagree" to seven "very strongly agree" (Zimet et al., 1988). Rationale for utilizing this tool is based on the design. The measurement tool was designed to measure perceived emotional social support from three sources: friends, family, and significant others. Items measure support from the various groups related to emotions needs, decisions, and problems (Zimet et al., 1998). Time needed to administer this portion of the survey is 5 to 10 minutes.

Reliability and Validity. This tool has been used with populations with chronic cardiovascular conditions, has sound psychometric properties, and will yield ordinal level data. The MSPSS has good internal and test-retest reliability, good validity, fairly stable factorial structure across studies and nationalities. Factor analysis confirmed the instrument validity for total score and separate data identified in the three subscales. Cronbach's alphas across for total scale (0.88) and the subscales of "Significant Other" (0.91), "Family" (0.87), and "Friends" (0.85) indicate good internal consistency across the scale. The instrument was confirmed for validity and reliability across subscales for individuals with an ICD and their partners. Cronbach's alpha for this ICD group ranges from 0.74 to 0.89 across all twelve items (Pedersen,

et al., 2009). The instrument was also revalidated for individuals with chronic conditions for reliability, Cronbach's alphas over 0.90, and validity of factor analysis of items showing consistency producing a three-factor solution across scales (Bugajski, et al., 2019).

Scoring. Subgroup's scores are obtained by adding across the four items and dividing by four. For a Total Scale score, all 12 items are added together and divided by 12. Higher scores correlate with greater support. As there are not established rules for scoring the MSPSS, mean scores can be used when addressing potential differences in norms such as ethnicity, age, gender, or marital status. Also, the option to divide participants into groups is available based on scores. There are two ways that can be done. The first option is to divide participants into three equal groups based on scores and designate them low, medium, and high support. The other option is to use the mean scores, with 1 to 2.9 meaning low, 3 to 5 as moderate, and 5.1 to 7 indicating high support. For these options equal distribution or skew need to be addressed (Zimet et al., 1988).

Dependent Variable

Psychosocial Well-Being

Description. Well-being in general is a subjective construct conceptually defined through social, psychological, and health-related dimensions (Diener et al., 1999). The DV psychosocial well-being will be conceptualized with this holistic approach in mind and a focus on the psychosocial aspects of living a good life as identified by Ryff (2014). The 42-item Psychological Wellbeing (PWB) scale will be used to operationalize the DV of psychosocial well-being. PWB includes seven items for each of the six subgroups within the scale distinguished as (a) autonomy, (b) environmental mastery, (c) personal growth, (d) positive relations with others, (e) purpose in life, and (f) self-acceptance. The survey is measured on a 6-

point Likert scale with one being “strongly disagree” and six being “strongly agree” (Ryff, 1989; Ryff & Keyes, 1995).

Reliability and validity. Instrument reliability and validity for the PWB has been consistent with 120-item, 84-item, 54-item, and 42-item scales. The 18-item scale is not recommended for use as it there were problems with psychometrics due to the scale being too condensed and not adequately evaluating the six concepts central to the instrument. The developers recommended using the 42-item scale if number of survey items is of concern, as reliability and validity were confirmed scales of 42 items and above. Cronbach’s alphas were obtained for all subgroups using the 20-items parent scale and with good correlation across lesser items scales: (a) autonomy 0.83, 0.97, (b) environmental mastery 0.86, 0.98, (c) personal growth 0.85, 0.97, (d) positive relations with others 0.88, 0.98, (e) purpose in life 0.88, 0.98, and (f) self-acceptance 0.91, 0.99 (Ryff, 1989). A study to address psychological concerns prior to ICD implant utilized the 42-item PWB scale found similar mean scores when compared to prior studies on chronic conditions (Gostoli et al., 2016). Multiple studies with aged populations and chronic conditions have been conducted using the PWB.

Scoring. Scoring for the PWB is the same for all scale lengths. An overall psychological well-being score is obtained by adding scores on the individual scales, and paying close attention to reverse-scored items, to obtain a composite score. Items with negative responses are reverse scored with an answer of “6” (strongly agree) valued as a “1,” for example. Level of psychological well-being can be assessed by analyzing distribution of scores and identifying the top 25% of scores as high and the bottom 25% as low or by assessing the SD (Ryff & Singer., 2006).

Higher scores on the PWB correlate with a greater sense of well-being. Each subgroup scoring provides greater depth to address concepts of well-being. An individual with higher scores in the "Autonomy" subgroup can be defined as having greater independence, resistance to social pressures, and self-regulation. The "Environmental Mastery" subgroup addresses an individual's ability to manage daily life, feel in control, and take advantage of opportunities. Higher scores correlate with improved mastery. Those individuals with high scores in the "Personal Growth" subgroup are more open to change and expansion of life. Individuals who have higher scores in the subgroup "Positive Relations" express empathy, trust, and greater intimacy with others, whereas those with lower scores tend to isolate and are less willing to compromise. The subgroup "Purpose in Life" correlates with a sense of meaning of life and goal setting, with higher scores related to greater feeling of purpose. And finally, the higher scores in the subgroup "Self-acceptance" correlate with a positive attitude toward self both in the present and the past (Ryff, 1989; Ryff & Keyes, 1995; Ryff & Singer, 2006; Ryff & Singer, 2008).

Table 3.1

Measuring and Scoring of Variables

Variable	Context	Measurements and Scoring	Cronbach's alpha
Independent Variables related to Uncertainty:	Identify factors related to uncertainty influencing living with an ICD	Florida Patient Acceptance Scale (FPAS) • 18 Items: 15 items in 4 subscales and 3 extra items • Describes living with a medical device • FPAS Total score = 1® + 2® + 3® + 4® + 5 + 6 + 7 + 8 + 10 + 12® + 13+ 14® + 15® + 17® + 18® for raw score, then raw score -15/60 * 100	0.83
Condition and Patient Characteristics	Identify factors related to severity of illness, knowledge of device, and individual characteristics influencing living with an ICD	Patient characteristics form FPAS - Knowledge of Device Items 11 16	N/A
Acceptance	Identify factors related to of the acceptance and return to life with an ICD	FPAS: Return to Life (subscale) Items 6 13 17® 18® Scale Score = (raw-4)/16 * 100 FPAS: Positive appraisal (subscale) Items 5 7 8 10 Scale Score = (raw-4)/16 * 100 FPAS: Return to Sex Life Items 9	0.77 0.88 N/A
Stress Appraisal	Identification of factors related to stress of living with an ICD	FPAS: Device-related Distress (subscale) Items 1® 2® 3® 4® 12® Scale Score = (raw-5)/20 * 100 FPAS: Body Image Concerns (subscale) Items 14® 15® Scale Score = (raw-2)/8 * 100	0.74 0.79

Variable	**Context**	**Measurements and Scoring**	**Cronbach's alpha**
Independent Variable: Social Facilitation	Identify presence, influence, and collaboration with intimate social network	Multidimensional Scale of Perceived Social Support (MSPSS) (12 items) Subgroups 4 Items each Special Person 1 2 5 10 Family 3 4 8 11 Friends 6 7 9 12 Mean scoring: Subscales sum items and divide by 4 Total scale score: Sum all items and divide by 12.	Total Scale: .77-.92 (mean = .87) Special Person: .79 to .98 (mean = .88) Family: .81-.93 (mean = .87) Friends: .78-.94 (mean =.88)
Dependent Variable: Psycho-social Well-Being	Identify aspects of Well-being related living a good life with an ICD	Psychological Well-being (PWB) Scale (42 Items; 6 subgroups) Subgroups 7 items each Autonomy 1 7 12 ® 19 ® 25 31® 37 Environmental Mastery 2 8® 14® 20 26® 32® 38 Personal growth 3 9 15® 21 27® 33 39® Positive relations 4 10® 16® 22 28 34® 40 Purpose in life 5® 11 17® 23® 29 35 41® Self-acceptance 6 12 18® 24 30® 36® 42 ® items should be reverse scored	Cronbach' s alpha 0.83 Cronbach's alpha 0.86 Cronbach's alpha 0.85 Cronbach's alpha 0.88 Cronbach's alpha 0.88 Cronbach's apha 0.91

(Burns et al., 2005; Ryff, 1989; Ryff & Keyes, 1995; Zimet, 1988)

Data Management Plan

The researcher implemented a data management plan to protect the data and streamline collection for analysis. Any paper copies of forms for the study were kept in locked file cabinets. Qualtrics software was utilized to collect data from the survey for the study. All data was entered into the most recent SPSS software file and stored on a password protected computer. Frequency distributions of all variables was checked before proceeding with the analysis. Data was checked for sufficient variability in the dependent measures. When 25% of the data was been collected, the researcher checked for any problems or skew. Beginning when 25% of the data has been collected, data was checked to ensure that assumptions for planned statistical analyses could be met. There were no cases with missing items or outcome scores of 5% or more to be considered for exclusion. Low recruitment problems arose and the statistical teams at the University of Wisconsin-Milwaukee, committee members, and the researcher worked together to make decisions about needed modifications. Modifications to the study recruitment strategies were logged and submitted to the IRB for approval before being implemented.

Data Analysis

Analysis of responses to measurement instruments included in this quantitative study will provide a controlled review of the variables identified in the study model (Yilmaz, 2013). Data analysis was conducted using the latest version of SPSS ® software version 28. The study aims and main research questions were be analyzed using multiple regression. The analysis examined associations between the independent variables "Knowledge," “Severity of cardiovascular condition,” “Individual Stress Appraisal,” “Acceptance of ICD,” and “Social facilitation,” and the dependent variable “Psychosocial Well-being.” The descriptive questions were analyzed using descriptive statistical analysis, including frequency distributions, means, and standard

deviations. Measures of variables did not have severely skewed distributions and did not need to be transformed or analyzed with non-parametric tests. Descriptive statistics were used to describe and summarize patient levels of knowledge, individual stress appraisal, acceptance, social facilitation, and psychosocial well-being (Polit & Beck, 2022).

Ethical Concerns and Confidentiality

Protection of human subjects was established by working directly with the IRB for regulation and approval of the study. The risk of the study is low to participants and the benefit outweighs the risk. Care was taken not to aggravate any underlying psychosocial issue, cause re-experiencing of trauma, or induce stress. Recruitment was completed with sensitivity to individuals with chronic conditions and without coercion. Individuals were allowed to withdraw from the study at any time. The survey was conducted in a manner to minimize fatigue and harm to individuals. Healthcare professionals were not coerced to promote recruitment. Patient identifiers were not included in the survey or used to save the data. The data was deidentified. Data was protected by use of computer password and encryption. During recruitment the researcher was sensitive when ensuring literacy of potential participants. No potential subjects were found to be illiterate and those who did not meet inclusion criteria were treated with respect and informed of exclusion from the study in an empathetic manner.

Chapter Summary

This quantitative descriptive correlation study addressing potential factors influencing the psychosocial well-being of individuals with an ICD has a significance for multidisciplinary care. This study will identify the relationships between uncertainty, social facilitation and well-being for adults living with an ICD. The potential uncertainty is high for adults facing of a life-threatening condition and living with an ICD. Screening to address the psychosocial needs

associated with uncertainty can improve the way individual self-manage their living with an ICD. Due to the expectation of a homogenous population, the data may not be generalizable to all populations. The COVID-19 pandemic may influence the findings due to the need for a restructuring of the recruitment and data collection process. Identifying factors influencing uncertainty related to living with an ICD may lead individuals toward an improved sense of psychosocial well-being.

Chapter Four: Findings

SPSS ® software version 28 was used to analyze the data reported in this chapter. Participants (N=100) for this investigation exceeded the expected number required to achieve a power at the .80 level with a probability of p =.05. Five descriptive questions and a predictive, association question was examined to assess the uncertainty, social facilitation, and well-being of participants living with an ICD. Uncertainty included findings from the measures of characteristics of the participants, their knowledge, stress appraisal, and acceptance of the ICD.

Sample Overview

Descriptive statistical analysis was performed to provide an overview of the sample, including mean, standard deviation, percentage, range, frequency, and distribution. Continuous variables assessed for mean, standard deviation, range, and distribution include (a) age, (b) BMI, (c) knowledge, (d) perception of uncertainty, (e) perception of social facilitation, and (f) perception of psychosocial well-being. Frequencies and percentages measured categorical variables for demographic (Table 4.1) and clinical (Table 4.2) patient characteristics, including (a) gender, (b) marital status, (c) ethnicity, (d) religion, (e) education, (f) income, (g) driving, (h) participation in support groups, and (i) health condition. The relationship between the demographic and clinical characteristic variables was examined for significance by conducting a Pearson's Correlation coefficient statistical analysis with a p-value < 0.05 for the high cutoff, < 0.01 for the medium cutoff, and <.001 for the lowest cutoff. Correlation strength was established using an r value with < 0.3 as a weak correlation, 0.3 to 0.7 a moderate correlation, and over 0.7 a strong correlation. Following the sample overview, the research questions explore perceptions of uncertainty, social facilitation, and psychosocial well-being.

Demographic Characteristics of Participants

A majority of individuals living with an ICD who participated in the study (n=100) were female (71%), less than 64 years of age (76%), White (87%), and married (54%) (Table 4.1). Most male participants (48%) were over 65 years and generally older than the women in this study. The age ranges of the participants were distributed evenly among young adults to midlife (36%), midlife to older adults (33%), and older adults (31%).

All participants had a minimum of a high school diploma/GED, with the majority (76%) having a college degree. More men (69%) completed higher education at the bachelor level or higher than women (52%). Participants with a higher education reported a higher annual salary (r = .424, p = <.001). Annual reported annual incomes varied, equally representing individuals making less than $50,000 (32%), an income of $50,000 to $100,000 (35%), or an income over $100,000 (31%). Men (76%) had a higher annual salary than women (62%). Of female respondents, 21% reported annual incomes of less than $30,000.

The participants remained active, with approximately 41% reporting working full- or part-time, though 59% were either not working or retired. Job changes for participants, including retirement, increased with age (r = .382, p = <.001). A majority (64%) of participants reported engagement in at least one or more groups for support or activities. Additionally, 72% reported religious affiliation, and 64% retained driving privileges.

Table 4.1

Demographic Characteristics of Participants

Characteristic	M	SD	Range
Age (years)	53.7	14.8	21-84
Height (inches)	66.3	4.1	59-76
Weight (lbs.)	189.9	46.7	85-319
Body Mass Index (kg/m2)	30.3	7.1	16.6-50.6

Characteristic	Full Sample[a]		Male		Female	
	n	%	n	%	n	%
Gender						
Male	29	—				
Female	71	—				
Age Categories						
18 to 49 years	36	—	4	14	32	45
50 to 64 years	33	—	11	38	22	31
65 to 85 years	31	—	14	48	17	24
Marital status						
Married	54	—	18	62	36	51
Domestic Partner	5	—	2	6	3	4
Single	26	—	6	21	20	28
Widowed	4	—	1	3	3	4
Divorced	11	—	2	7	9	12
Race/Ethnicity						
Caucasian/White	87	—	25	86	62	87
African American/Black	2	—	1	3	1	1
Asian/Pacific Islander	1	—	0	0	1	1
Hispanic, Latino, Latin American	7	—	1	3	6	8
Middle Eastern	0	—	0	0	0	0
Other	3	—	2	7	1	1
Religion						
Christian	22	—	4	14	18	25
Protestant	7	—	6	21	5	7
Catholic	25	—	8	27	17	24
Jewish	3	—	1	3	2	3
Islam	0	—	0	0	0	0
Other	16	—	9	31	7	10
None	26	—	5	17	21	29

Characteristic	Full Sample[a]		Male		Female	
	n	%	n	%	n	%
Highest educational level						
<12 years of school	0	—	0	0	0	0
High School / GED	24	—	3	10	21	29
Associates	19	—	6	21	13	18
Bachelors	29	—	6	21	23	32
Masters or higher	28	—	14	48	14	20
Annual Family Income						
Less than $30,000	15	—	0	0	15	21
$30,000 - $50,000	17	—	6	21	11	15
$50,000 - $100,000	35	—	11	38	24	34
Over $100,000	31	—	11	38	20	28
Chose not to answer	2	—	1	3	1	1
Job Change or Loss Post Device						
No	41	—	12	41	29	41
Yes	36	—	7	24	29	41
Retired	23	—	10	34	13	18
Driving Restriction						
Never	64	—	18	62	46	64
Short Time after Implant	13	—	5	17	8	11
For 3 months	8	—	3	10	5	7
For 6 months	4	—	0	0	4	6
Don’t Drive at All	9	—	2	7	7	10
Lost Driving Privileges	2	—	1	3	1	1
Group Participation						
Neighborhood	30	—	11	38	19	27
Church	24	—	11	38	13	18
Work	24	—	4	14	20	28
Sports	22	—	5	17	17	24
Political	8	—	3	10	5	7
Support	20	—	5	17	15	21
Number of Groups Participation						
None	32	—	8	27	24	34
One or Two	52	—	18	62	38	53
Three or More	12	—	3	10	9	12

Note. $N = 100$. Total percentages may not equal 100% due to missed values.

[a]The *n* and percentage for variables are the same in the full sample.

Clinical Characteristics of Participants

A majority of participants (63%) shared that the decision to implant the ICD was secondary to arrhythmias (24%), congestive heart failure (15%), or low EF (11%), as well as a range of other conditions (Table 4.2). More males reported having diabetes (r = .307, p = .002), atrial fibrillation (r = .208, p = .038), or high blood pressure (r = .239, p = .017), whereas females reported more genetic heart conditions (r = .226, p = .024). A fourth of the participants, primarily female, reported having been diagnosed with a mental health condition (25%). Complications occurred in nearly one-third of participants (32%), including 26% who experienced errors with technology or infection (10%). A high number of participants reported being obese (46%), with BMIs ranging from 16.6 to 50.6, with mean of 30.3 (SD=7.1), across men and women.

Over two-thirds of the participants (66%) were non-smokers who exercised regularly (84%) at a mild (40%) or moderate (38%) level. Most participants lived independently (87%). Individuals needing assistance with activities of daily living frequently were non-White (r = .279, p = .005), less educated (r = -.301, p = .002), had a lower income (r = .034, p =.002), were less physically active (r = .327, p = <.001), had driving restrictions (r = .384, p = <.001), and had a history of smoking (r = .406, p = <.001).

Table 4.2

Clinical Characteristics of Participants

Characteristic	Full Sample[a]		Male		Female	
	n	%	n	%	n	%
Gender						
Male	29	—				
Female	71	—				
Number of ICD procedures						
One	62	—	16	55	46	65
Two	18	—	5	17	13	18
Three	10	—	5	17	5	7
Four	2	—	0	0	2	3
Five or More	8	—	3	10	5	7
ICD procedure complications						
Dislodged Lead	6	—	1	3	5	7
Broken Lead	11	—	3	10	8	11
Device or Lead Recall	9	—	3	10	6	8
Infection	10	—	0	0	10	14
Inappropriate Shock(s)	9	—	3	10	6	8
Number of complications						
None	68	—	23	79	45	63
One	23	—	3	10	20	28
Two or More	9	—	3	10	6	8
Reported Reason for Implant						
Prevent Sudden Death	26	—	4	13	22	31
Cardiac Arrest or Arrhythmia	57	—	20	69	37	52
Other	17	—	5	17	12	17
Primary Prevention	39	—	8	27	31	44
Secondary Prevention	61	—	21	72	40	56
ICD Shock(s)						
Never	63	—	14	48	49	69
One Time	15	—	8	27	7	10
Two Separate Times	6	—	1	3	5	7
Three or More Times	16	—	6	21	10	14
Multiple Shocks in a Day	18	—	8	27	10	14
Comorbidities						
Mental Health Condition	25	—	4	13	21	29
Diabetes	12	—	8	27	4	6
Genetic Heart Condition	34	—	5	17	29	41
Weakened Heart Muscle	54	—	16	55	38	53
Atrial Fibrillation	33	—	14	48	19	27
Congestive Heart Failure	47	—	15	52	19	27
High Blood Pressure	34	—	16	55	46	65

Characteristic	Full Sample[a]		Male		Female	
	n	%	n	%	n	%
Number of Cardiovascular Comorbidities						
None	11	—	1	3	10	14
One or Two	53	—	19	65	34	49
Three or more	36	—	9	31	27	38
Smoking History						
Never Smoker	66	—	17	57	49	69
Currently smoking (varied amount)	5	—	1	3	6	6
Half Pack Daily	1	—	0	0	1	1
More than One Pack Daily	1	—	0	0	1	1
Another amount Daily	4	—	2	7	2	3
Former Smoker	27	—	9	31	18	25
Declined to answer	1	—	1	3	0	0
BMI Categories[c]						
Underweight (BMI <18.5)	2	—	0	0	2	3
Healthy weight (BMI 18.5-24.9)	23	—	5	17	18	25
Overweight (BMI 25-29.9)	29	—	11	38	18	25
Obese (BMI 30-40)	34	—	11	38	23	32
Severely Obese (BMI >40)	12	—	2	7	10	14
Help needed with ADLs[d]						
Lives Independently	87	—	27	93	60	84
Some help laundry/cooking	11	—	2	7	9	13
Weekly bathing/shopping	1	—	0	0	1	1
Dependent on Others	1	—	0	0	1	1
Physical Activity						
Everyday	52	—	18	62	34	48
Every Other Day	32	—	9	31	23	32
Once or Twice a Week	11	—	1	3	10	14
None	5	—	1	3	4	4
Physical Activity Level						
Mild	40	—	9	31	31	44
Moderate	38	—	12	41	26	37
Moderate to Intense	16	—	6	21	10	14
Intense	1	—	1	3	0	0
No Activity	5	—	1	3	4	6

Note. $N = 100$. N may not equal 100 due to missing values.

[a]The *n* and percentage for variables are the same in the full sample. [b]Implantable Cardioverter Defibrillator (ICD). [c]Body Mass Index (BMI). [d]Activities of Daily Living (ADL).

Descriptive Research Questions

Descriptive findings from the **“**Uncertainty”, “Social Facilitation”, and “Psychosocial Well-Being” measures explore participant levels of perceptions. Research questions one through three examine levels of perception uncertainty related to knowledge, severity of condition, stress appraisal, and acceptance. Research question four examines levels of perception of support for social facilitation. Finally, research question five examines perceptions of psychosocial well-being.

Perceived Level of Uncertainty Measures

Florida Patient Acceptance Survey (FPAS) total scores reflected the overall uncertainty of individuals living with an ICD based on their acceptance and adjustment to life with an ICD and device-related distress. FPAS subscales of uncertainty and participant clinical characteristics were assessed by (a) severity of condition and device knowledge, (b) device-related distress, and (c) device acceptance. The first three study questions measured the participant's severity of condition, knowledge, stress appraisal, and acceptance of living with an ICD. Descriptive analysis of the responses to FPAS, including mean, standard deviation, and range, are discussed. Cronbach's alpha over 0.70 for the FPAS total and subscales demonstrated good reliability and internal consistency (Table 4.3).

General Uncertainty

The FPAS total scores ranged from 28 to 100, with a mean of 80 (*SD*=17.1) (Table 4.3). Based on the FPAS total scores, most participants reported high (47%) to moderate (25%) acceptance and adjustment to living with the ICD and low device-related distress (Table 4.4). More female participants (31%) reported lower acceptance and more stress living with an ICD, as reflected in their lower FPAS total scores than males (14%).

Table 4.3

Psychometric Properties for Measurement Instruments

Measurement Instrument	N	Mean	Std. Deviation	Range	Cronbach's Alpha
FPAS TOTAL Score[a]	98	80	17.1	28-100	.860
FPAS Subscale					
Return to Life	99	73	27.6	0-100	.741
Positive Appraisal	100	86	22.5	0-100	.899
Device-Related Distress	100	77	21.7	5-100	.763
Body Image	99	87	21.3	13-100	.744
FPAS Knowledge	100	8	1.8	2-10	.865
MSPSS Total Score[b]	100	5.9	1.3	1.4-7	.947
MSPSS Subscale					
Special Person	100	6.3	1.3	1-7	.917
Family	100	5.7	1.5	1-7	.942
Friends	100	5.7	1.5	1.5-7	.935
PWB Total Score[c]	96	199	30.2	118-247	.940
PWB Subscale					
Autonomy	99	33	5.8	16-42	.758
Environmental Mastery	98	32	7.3	12-42	.861
Personal Growth	99	34	5.7	18-42	.778
Positive Relations	100	36	6.3	15-42	.808
Purpose Life	100	33	5.8	18-42	.710
Self-Acceptance	100	31	6.8	14-42	.824

Note. N=100. *N* may not equal 100 due to missing values.

[a]Florida Patient Acceptance Survey (FPAS). [b]Multidimensional Scale of Perceived Social Support (MSPSS). [c]Psychological Well-being Scale (PWB).

Table 4.4

Frequencies for Measurement Instrument Score Categories

Measurement Score Categories	Full Sample[a]		Male		Female	
	n	%	n	%	n	%
FPAS Score Categories[b]						
High Score (>86)[c]	47	—	15	53	32	46
Moderate Score (70 to 85)	25	—	9	32	16	23
Low Score (<70)	26	—	4	14	22	31
MSPSS Score Categories[d]						
High Score (6.5 to 7)[e]	49	—	14	48	35	49
Moderate Score (5.5 to 6.4)	29	—	8	28	21	30
Low Score (<5.5)	22	—	7	24	15	21
PWB Score Categories[f]						
High Score (>220)[g]	31	—	10	37	21	30
Moderate Score (180 to 219)	40	—	14	52	26	38
Low Score (<180)	25	—	3	11	22	32

Note. N=100. The *n* and percentages may not equal 100% due to missing values.

[a]The *n* and percentage for variables are the same in the full sample.

[b]Florida Patient Acceptance Survey (FPAS). [c]FPAS maximum score is 100.

[d]Multidimensional Scale of Perceived Social Support (MSPSS). [e]MSPSS maximum score is 7.

[f]Psychological Well-being Scale (PWB). [g]PWB maximum score is 252.

Research Question One: Knowledge and Condition

What is the knowledge level among adults with an ICD and their severity of condition?

Knowledge. Knowledge was measured by participant's responses to two FPAS knowledge questions. Participants reported understanding the ICD and how it works, with a high FPAS "Knowledge" mean score of 8 (*SD*=1.8) (Table 4.3). A significant correlation was found between participant's knowledge of the ICD and what it does for them and church group membership (r = .221, p = .027). Participants who had received multiple ICDs through subsequent replacements reported greater knowledge and understanding of the ICD (r = .345, p = <.001), suggesting that having multiple ICDs increases individual's knowledge of how the device works and what it does for them. Participants with broken wires tended to be less knowledgeable about the ICD (r = -.212, p = .034). FPAS knowledge had no significant correlations with other variables in the study.

Participants Condition. Descriptive findings on participant demographic and clinical characteristics provide an overview of the general health and condition of participants. The severity of the condition was measured by the number of comorbidities, criterion for placing the ICD implant, and the prevalence of ICD shocks.

Comorbidities. A majority of the participants reported having at least one comorbidity (89%), with higher numbers of comorbidities correlated with older age (r = .230, p = .022), and higher BMI (r = .230, p = .022). Participants with a higher number of cardiovascular comorbidities were more likely to have a weakened heart muscle (r = .644, p = <.001), atrial fibrillation (r = .558, p = <.001), congestive heart failure (r = .573, p = <.001), or hypertension (r = .380 p = <.001). Individuals with a genetic condition reported fewer cardiovascular comorbidities (r = .281, p = <.001) were younger (r = .226, p = .024) and more often women.

Participants who reported a weakened heart muscle often experienced congestive heart failure (r = 0.507; p = <0.001) or atrial fibrillation (r = 0.306; p = 0.002).

Reason for ICD Implant. A majority of participants were living with their first ICD (62%). Most participants (61%) had their original device implanted following a life-threatening arrhythmia or cardiac arrest, while 39% received the ICD implant due to risk of SCA. More individuals implanted for secondary prevention were college educated (r = .232, p = .020), had annual income over $50,000 ($r$ = .313, p = .002), and engaged in more intense physical activity (r = .206, p = .040). The presence of a weakened heart muscle (r = 0.285, p = 0.004) and congestive heart failure (r = 0.438, p = <0.001) more often correlated with receiving an ICD for secondary prevention.

ICD Shocks. Over one-third of participants (37%) reported one or more ICD shocks, and half of those individuals (18%) experienced multiple shocks in one day. Higher numbers of ICD shocks were correlated with a history of more procedures (r = .323, p = <.001), complications (r = .236, p = .018), and multiple shocks in a day (r = .520, p = .001). Shocks for non-life-threatening reasons occurred with a higher number of device procedures (r = .525, p = <.001) or a higher number of ICD complications (r = .622, p = <.001). A significant number of participants with inappropriate shocks experienced a shock storm of multiple shocks in one day (r = .580, p = .012).

Research Question Two: Stress Appraisal

What is the individual stress appraisal among adults with an ICD?

Device-related Distress. Stress appraisal was measured by responses to FPAS device-related distress questions. Scores for FPAS subscale "Device-related Distress" (77, *SD* = 21.7)

indicate varied experiences among participants in managing stress (Table 4.3). Participants who were younger (r = .384, p = <.001), had less income (r = .270, p = .007), a job loss or change (r = .207, p = .039), or restricted driving (r = .212, p = .034), tended to have more device-related distress. Conditions that correlated with participants having more device-related stress include mental health (r = .245, p = .014), genetic heart condition (r = .250, p =.012), and congestive heart failure (r = .205, p = .041). Although participants implanted for secondary prevention tended to have more device-related stress than those implanted for primary prevention (r = .211, p = .035), ICD shocks and complications did not directly correlate. The majority of participants did not feel depressed (61%) when thinking about the device.

Body Image. Individual stress appraisal was also measured by responses to FPAS body image questions. Most participants had a positive view of themselves, with a FPAS "Body Image" subscale mean of 87 (*SD*=21.3) (Table 4.3). Younger participants (r = .479, p = <.001) reported a significantly lower body image. Participants who attended church groups reported higher body image scores (r = .270, p = .007).

Research Question Three: Acceptance

What is the acceptance level of an ICD among adults with an ICD?

Participants acceptance of living with their ICD was measured using the FPAS "Return to Life" subscale, FPAS "Positive Appraisal" subscale, and the FPAS "Return to Sex Life" question. Higher scores reflect the participant's ability to return life experienced prior to receiving an ICD. Expressing a positive view of the ICD also signifies acceptance of the device.

Return to Life. Scores on the FPAS subscale "Return to Life" (73, *SD*=27.6) indicate varied life experiences living with an ICD (Table 4.3), but a majority reported returning to work (77%) and physical activity (71%). Participants with higher levels of college education (r = .332;

p = <.001) and income (r = .347; p = <.001) reported an easier time adjusting to life with the ICD. Participants with more comorbidities (r = .289; p = .004), a weakened heart muscle (r = .257; p = .010), congestive heart failure (r = .419; p = <.001), or a mental health condition (r = .237; p = .018) reported less ability to return to life after the ICD. Attending more groups improved participant's ability to return to life with an ICD (r = .266; p = .008). Independence with activities of daily living (r = .537; p = <.001), engaging in physical activity (r = .384; p = <.001), or ability to drive (r = .298; p = .003) enhanced adjustment to life with an ICD. Also, participants with a higher number of comorbidities (r = .247; p =.014) or congestive heart failure (r = .262; p = .009) had more difficulty returning to their prior sex life.

Positive Appraisal. Most participants had a positive attitude about living with the ICD, with a FPAS "Positive Appraisal" mean of 86 (*SD*=22.5). Most participants reported the positives of the ICD outweighed the negatives (86%), feel safer with an ICD (82%), and would receive the ICD again (83%). Participants of ethnicities other than White reported a less positive experience with the ICD (r = .200; p = .046). Experiencing more complications (r = .266; p = <.008), including a broken lead (r = .221; p = .027), infection (r = .252; p = .012), or inappropriate ICD shocks (r = .218; p = .029) negatively impacted participant's ability to remain optimistic about the ICD.

Perceived Level of Social Facilitation Measure

The MSPSS measured the variable of social facilitation. Cronbach's alpha for the Total MSPSS and subscales show good reliability and internal consistency (Table 4.3).

Research Question Four: Social facilitation

What is the level of social facilitation among adults with an ICD?

Most participants (78%) had moderate to high total MSPSS scores, with a mean of 5.9 (*SD*=1.8), indicating moderate to high levels of support from others (Table 4.3). MSPSS score distribution is similar for men and women, showing no differences in support across gender (Table 4.4). Participants reported more support from a spouse or partner (mean = 6.3, *SD*=1.3), than family (mean = 5.7, *SD* = 1.5) or friends (mean = 5.7, *SD* = 1.5). Participants with a higher income level reported higher levels of education (r = .424; p = <0.001) and support from others (r = .222, p = .026). Those with annual incomes over $50,000 engaged in various groups (r = .199, p = .048) for support and activities outside their neighborhoods, but individuals with annual income less than $50,000 sought support from neighborhood groups (r = .298; p = .003). Participants with congestive heart failure (r = .270, p = .007) felt supported by family and friends, whereas individuals needing help with activities of daily living (r = .254, p = .011) reported less support.

Perceived Level of Psychosocial Well-Being Measure

The PWB measured the variable of psychosocial well-being. Cronbach's alpha for the Total PWB and subscales show good reliability and internal consistency (Table 4.3).

Research Question Five: Psychosocial Well-Being

What is the level of psychosocial well-being among adults with an ICD?

Psychosocial well-being was measured using the psychological well-being (PWB) total score and the subscale scores within it including autonomy, environmental mastery, personal growth, positive relations, purpose of life, and self-acceptance. Analysis of subscale correlations provided a clearer picture of participant perceptions of psychosocial well-being.

PWB total. Most participants (71%) reported moderate to high levels of psychosocial well-being, with a mean PWB total score of 199 (*SD*=30.2). More women (32%) reported lower

psychological well-being than males (11%). Living independently (r = .402, p = <.001), engaging in physical activity (r = .418, p = <.001), being college educated (r = .268, p = .008), or having a higher annual income (r = .369, p = <.001) positively increased levels of psychosocial well-being. Participants with higher BMI (r = .308, p = .002), a mental health condition (r = .530, p = <.001), or congestive heart failure (r = .333, p = <.001) reported lower psychosocial well-being. Participants who received the ICD after a cardiac arrest or life-threatening arrhythmia (r = .232, p = .023) reported higher levels of psychosocial well-being compared to those receiving the ICD as a precautionary measure. Conversely, participants who received a shock (r = .231, p = .024) or lost driving privileges (r = .230, p = .024) reported lower psychosocial well-being. Attending more groups (r = .254, p = .012) positively influenced psychosocial well-being.

PWB subscales. PWB subscales had similar means and distribution (Table 4.3). Older participants (r = .243, p = .015) and those with more understanding of the ICD (r =.207, p =.039) reported higher perceptions of autonomy. Most participants could voice their opinions (77%) without worrying about what others may think (48%). Participants reported being in control of their situations (67%) and able to manage daily life (75%). Even so, half of participants felt overwhelmed and sad at times. Perceptions of mastery over the environment increased with age (r = .405, = <.001), higher education (r = .220, p = .030), higher annual income (r = .377, p = <.001), being male (r = .230, p = .023), and engaging in more physical activity (r = .394, p = <.001), but decreased for participants with an ethnicity other than White (r = .252, p = .012), a higher BMI (r = .280, p = .005), and less ability to manage ADLs (r = .356, p = <.001). Participants with a genetic condition (r = .289, p = .004) or congestive heart failure (r = .297, p = .003) reported more difficulty mastering their environment. Conversely, participants with

hypertension reported more mastery over their environment (r = -.210, p =.038). Participants receiving an ICD post-cardiac arrest or arrhythmia reported positive mastery over the environment after the ICD implant (r = .218, p = .031). In contrast, participants experiencing ICD shocks (r = .199, p = .049) or driving restriction after implant (r = .230, p = .023) had less ability to master their environment.

A majority of participants remain open to new experiences that improve their growth (82%) but struggle with change in familiar patterns (62%). Participants with higher education (r = .299, p = .003), higher annual income (r = .315, p = .002), attending more social groups (r = .203, p = .044), and engaging in more physical activity (r = .200, p =.047) reported improvements in personal growth. In contrast, participants unable to manage their ADLs (r = .375, p = <.001) or who had debilitating comorbidities such as congestive heart failure (r = .241, p = .016) reported less ability to grow personally. Participants having a cardiac arrest or arrhythmia before the ICD implant reported positive personal growth (r = .271, p = .007).

Most participants viewed themselves as a positive addition (81%) to their relationships that allowed for maintaining close relationships (65%) that are engaging (88%) and trustworthy (85%). Participants with a higher income (r = .267, p = .007) or who were physically active (r = .307, p =.002) reported more ability to maintain positive relationships. Relationship status was negatively affected by the inability to manage ADLs (r = .380, p = <.001), drive (r = .201, p = .045), or maintain a healthy weight (r = .224, p = .025). Participants of ethnicity other than White reported fewer positive relationships (r = .232, p = .020). Participants who attended more social groups reported more positive relationships (r = .257, p = .010), especially with work groups (r = .226, p = .024).

Most participants reported feeling positive and confident about themselves (67%) and how their lives turned out (53%). Self-acceptance improved for participants with age (r = .276, p = .005), higher education (r = .223, p = .026), higher annual income (r = .385, p = <.001), and engagement in physical activity (r = .331, p = <.001). Participants with hypertension (r =.228, p = .022) or cardiac arrest before the ICD implant (r = .269, p = .007) reported an improved sense of self compared to those with congestive heart failure who had less (r = .428, p = <.001). Participants who could not maintain a healthy weight (r = .324, p = .001), live independently (r = .318, p = .001), or were of an ethnicity other than White reported less self-acceptance (r = .293, p = .003).

Having a history of mental health struggles negatively correlates with all aspects of the subscales within the PWB scale, including perceptions of less autonomy (r = .409, p = <.001), less ability to master their environment (r = .547, p = <.001), less purpose in life (r = .323, p = .001), less ability to grow personally (r = .307, p = .002), less ability to build positive relationships (r = .341, p = <.001), and less acceptance of themselves (r = .468, p = <.001).

Multiple Regression Statistics

Simultaneous multiple regression was used to test the ability of severity of the condition, individual stress appraisal, acceptance of ICD, and social facilitation to predict psychosocial well-being. First, a Pearson's Correlation coefficient statistical analysis was conducted to examine the relationship between the independent and dependent variables to test for multicollinearity. For psychosocial variables, a strong correlation is measured with an r value of 0.7, with most correlations between 0.2 and 0.4 (Polit & Beck, 2008).

Research Question Six: Predictions and Associations

What are the associations between knowledge, severity of condition, individual stress appraisal, acceptance of ICD, overall uncertainty, and social facilitation with psychosocial well-being among adult participants with an ICD?

Hypothesis

Controlling for age and gender, knowledge, severity of condition, individual stress appraisal, acceptance of ICD, overall uncertainty, and social facilitation will predict psychosocial well-being in adults with an ICD.

Correlations Between the Independent and Dependent Variables

Correlations between independent and dependent variables were explored. Age, gender, and all independent variables, except for number of comorbidities, significantly correlated with the dependent variable psychosocial well-being (Table 4.5). Male participants tended to be older than female participants in this study. Number of comorbidities increased with age of participants (r =.230, p = .022). Even so, FPAS "Device-Related Distress" and FPAS "Body Image" (r =.278, p = .005) scores indicate less distress and improved body image with advancing age. FPAS total scores trended higher with progressive age (r =.313, p = .002), indicating higher adjustment and acceptance for older participants. Participants with an ICD for primary prevention were more likely to have a higher number of comorbidities than those implanted for secondary prevention (r =.339, p = .001). Participants experiencing more shocks reported higher FPAS "Total Score" (r =.246, p = .014), FPAS "Return to Life" (r =.214, p = .033), and FPAS "Positive Appraisal" (r =.278, p = .005) scores, indicating higher adjustment and acceptance of the ICD in these circumstances. Secondary prevention indication correlated with less FPAS "Device-Related Distress" (r =.211, p = .035) and higher FPAS total scores (r =.231, p = .022),

indicating lower stress appraisal and higher acceptance. Participants with higher MSPSS scores had higher FPAS total scores (r =.433, p = <.001) indicating increased acceptance of the ICD in the presence of more support. The correlation of independent variables MSPSS total score with FPAS total score and FPAS sub scores indicate a mediating relationship between these variables as hypothesized in the study framework (Figure 3).

Simultaneous Multiple Regression

Simultaneous multiple regression was conducted with separate models for knowledge and severity of condition, individual stress appraisal, acceptance of ICD, overall uncertainty, and social facilitation to predict psychosocial well-being. Therefore, hypotheses were delineated for each model controlling for age and gender to predict psychosocial well-being in adults with an ICD. All model variables in the study framework met assumptions of multiple linear regression to be included in the models (Polit & Beck, 2017). All study measures were reliable, with Cronbach's Alpha over 0.70 (Table 4.3). The relationship between the dependent and independent variables is linear on the scatter plot of the dependent variable for all models. Multicollinearity is not present in any of the models with predictor variables having low VIF values. The residuals for all models had homoscedasticity as they are independent without clustering of the sample, and data was not collected at different times. Furthermore, the residual was normally distributed with a standard P-P plot of regression-standardized residual scattered around the regression line for all models.

Table 4.5

Pearson Correlations for Study Model Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. PWB[a] Total Score	—											
2. Gender	-.206* .044	—										
3. Age	.266** .009	-.339** .001	—									
4. Number of Comorbidities			.230* .022	—								
5. Reason for Implant	.232* .023			-.265** .008	—							
6. ICD[b] Shocks	-.231* .024					—						
7. FPAS[c] Total Score	.607*** <.001		.313** .002		.231* .022	.246* .014	—					
8. FPAS Return to Life	.656*** <.001			-.289** .004		.214* .033	.811*** <.001	—				
9. FPAS Positive Appraisal	.228* .025					.278** .005	.617*** <.001	.286** .004	—			
10. FPAS Device-Related Distress	.462*** <.001		.384*** <.001		.211* .035		.841*** <.001	.604*** <.001	.267** .007	—		
11. FPAS Body Image	.226* .028		.479*** <.001				.475*** <.001			.373*** <.001	—	
12. MSPSS[d] Total Score	.590*** <.001						.433*** <.001	.330** .001	.345*** <.001	.291** .003	.247* .014	—

Note: [a]Psychological Well-Being Scale (PWB). [b]Implantable Cardioverter Defibrillator (ICD). [c]Florida Patient Acceptance Survey (FPAS).

[d]Multidimensional Scale of Perceived Social Support (MSPSS). The variable FPAS knowledge subscale had no correlations.

*p<.05. **p<.01. ***p<.001.

Regression Model One: Knowledge and Condition.

Adjusting for age, gender, the variables to assess severity of condition and FPAS "Knowledge" were added to regression model one to examine associations with psychosocial well-being. Variables to assess severity of condition included the "Number of Comorbidities" and "ICD Shocks", and "Reason for Implant". A multiple regression was calculated to predict psychosocial well-being based on the variables. The model significantly predicted 17% of the variance in psychosocial well-being, (F (6, 89) = 4.14, p = .001 (Table 4.6). The number of "ICD Shocks" negatively predicted participant psychosocial well-being (p = .004). "Age" positively predicted psychosocial well-being (p = .031). "Reason for Implant" positively predicted psychosocial well-being with a p value at the cutoff of significance (p = .05). Participants' predicted psychosocial well-being is equal to 175.12 – 7.48 (ICD Shocks) + 0.48 (Age) + 12.48 (Reason for Implant), where "ICD Shocks" are coded as number of shocks, "Age" is coded in years, and "Reason for Implant" is coded as 1 for primary prevention and 2 for secondary prevention. Participant psychological well-being scores decreased by 7.48 for each increase in number of shocks, increased by 0.48 for each increase in year of age, and increased 12.43 points for secondary prevention reason for implant. "Age", "ICD Shocks", and "Reason for Implant" were significant predictors of psychosocial well-being. "Gender", "Number of Comorbidities", and FPAS "Knowledge" were not significant predictors of psychosocial well-being.

Table 4.6

Regression of Associations of Condition and Knowledge with Psychosocial Well-Being

Variable	B	*SE* B	*β*	*t*	*p*
(Constant)	175.12	30.13		5.81	<.001***
Age	.48	.22	.23	2.20	.031*
Gender	-6.99	6.99	-.10	-1.00	.320
Number of Comorbidities	-5.96	4.83	-.13	-1.23	.221
Reason for Implant	12.43	6.29	.20	1.98	.05*
ICD[a] Shocks	-7.48	2.55	-.28	-2.94	.004**
FPAS[b] Knowledge	2.01	1.61	.12	1.25	.216
Model One Summary	F (6, 89) = 4.14	*p* =.001**	R^2 = .22	adjusted R^2 = .17	

Note. N=100. Dependent Variable: Psychological Well-Being Scale (PWB) Total Score.

Predictors: (Constant), Age, Gender, Number of Comorbidities, Reason for Implant,

[a] Implantable Cardioverter Defibrillator (ICD) Shocks, [b] Florida Patient Acceptance Survey (FPAS) Knowledge questions.

*p<.05. **p<.01. ***p<.001.

Regression Model Two: Stress Appraisal.

Adjusting for age, gender, the variables to assess stress appraisal, (a) FPAS subscale "Device-Related Distress" and (b) FPAS subscale "Body Image" were added to the regression model two to examine associations with psychosocial well-being. A multiple regression was calculated to predict psychosocial well-being based on the variables. The model significantly predicted 21% of the variance in psychosocial well-being, F (4, 90) = 7.43, p = <.001 (Table 4.7). FPAS "Device-Related Distress" positively predicted participant psychosocial well-being (p = <.001). Participant's predicted psychosocial well-being is equal to 163.22 + 0.61 (FPAS Device-Related Distress), where FPAS "Device-Related Distress" is coded by reverse scores with higher scores reflecting lower distress. Participants' psychological well-being increased by 0.61 points for each point of increase in FPAS "Device-Related Distress". FPAS "Device-Related Distress" was a significant predictor of psychosocial well-being. "Age", "Gender", and FPAS "Body Image" were not significant predictors of psychosocial well-being.

Table 4.7

Regression of Associations of Stress Appraisal with Psychosocial Well-Being

Variable	B	*SE* B	*β*	*t*	*p*
(Constant)	163.22	20.10		8.12	<.001***
Age	.05	.24	.02	.19	.848
Gender	-9.66	6.54	-.14	-1.48	.143
FPAS[a] Device-Related Distress	.61	.14	.44	4.22	<.001***
FPAS Body Image	.03	.15	.02	.20	.842
Model Two Summary	F (4, 90) = 7.43	*p* = <.001***	R^2 = .25	adjusted R^2 = .21	

Note. N=100. Dependent Variable: Psychological Well-being Scale (PWB) Total Score.

Predictors: (Constant), Age, Gender, [a] Florida Patient Acceptance Survey (FPAS) subscale Device-Related Distress, FPAS subscale Body Image.

*p<.05. **p<.01. ***p<.001.

Regression Model Three: Acceptance.

Adjusting for age, gender, the variables to assess acceptance, FPAS subscale “Return to Life”, FPAS question “Return to Sex Life”, and FPAS subscale “Positive Appraisal” were added to the regression model three to examine associations with psychological well-being. A multiple regression was calculated to predict psychosocial well-being based on the variables. The model significantly predicted 45% of the variance in psychosocial well-being, F (5, 88) = 16.04, p = <.001 (Table 4.8). Both FPAS “Return to Life” (p = <.001) and “Age” (p = .024) positively predicted psychosocial well-being. Participants’ predicted psychosocial well-being is equal to 129.82 + 0.68 (FPAS Return to Life) + 0.39 (Age), where FPAS “Return to Life” is coded positively by score and "Age” is coded in years. Participant psychosocial well-being increased by 0.68 for each point increase in FPAS in “Return to Life” scores and increased by 0.39 for each year of age. Both “Age” and FPAS “Return to Life” were significant predictors of psychosocial well-being. “Gender”, FPAS “Positive Appraisal”, and FPAS “Return to Sex Life” were not significant predictors of psychosocial well-being.

Table 4.8

Regression of Associations of Acceptance with Psychosocial Well-Being

Variable	B	*SE* B	*β*	*t*	*p*
(Constant)	129.82	18.97		6.85	<.001***
Age	.39	.17	.19	2.30	.024*
Gender	-1.45	5.56	-.02	-.26	.795
FPAS[a] Return to Life	.68	.10	.63	7.11	<.001***
FPAS Positive Appraisal	-.01	.11	.00	-.06	.956
FPAS Return to Sex Life	.43	1.99	.02	.21	.831
Model Three Summary	F (5, 88) = 16.04	*p* = <.001***	R^2 = .48	adjusted R^2 = .45	

Note. N=100. Dependent Variable: Psychological Well-being Scale (PWB) Total Score.

Predictors: (Constant), Age, Gender, [a] Florida Patient Acceptance Survey (FPAS) Subscale Return to Life, FPAS Subscale Positive Appraisal, and FPAS Return to Sex Life question.

*p<.05. **p<.01. ***p<.001.

Regression Model Four: Uncertainty.

Adjusting for age, gender, the variables to assess overall uncertainty including "Number of Comorbidities", "ICD shocks", "Reason for Implant", and FPAS "Total Score" were added to the regression model four to examine associations with psychosocial well-being. A multiple regression was calculated to predict psychosocial well-being based on the variables. The model significantly predicted 38% of the variance in psychosocial well-being, F (6, 87) = 10.66, p = <.001 (Table 4.9). ICD shocks (p = .029) negatively predicted psychological well-being. FPAS "Total Score" (p = <.001) positively predicted psychological well-being. Participant's predicted psychosocial well-being is equal to 138.70 + 0.91 (FPAS Total Score) – 4.89 (ICD Shocks), where FPAS "Total Score" is coded positively by score and "ICD Shocks" is coded by number of shocks. Participants' psychosocial well-being scores increased by 0.91 for each point increase in FPAS "Total Score" and decreased by 4.89 for each increase in number of shocks. Both "ICD Shocks" and FPAS "Total Score" were significant predictors of psychosocial well-being. "Age", "Gender", "Number of Comorbidities", and "Reason for Implant" were not significant predictors of psychosocial well-being.

Table 4.9

Regression of Associations of Uncertainty with Psychosocial Well-Being

Variable	B	*SE* B	*β*	*t*	*p*
(Constant)	138.70	23.70		5.85	<.001***
Age	.09	.20	.05	.48	.630
Gender	-6.64	6.00	-.10	-1.11	.272
Number of Comorbidities	-3.32	4.24	-.07	-.78	.437
ICD[a] Shocks	-4.89	2.21	-.19	-2.21	.029*
Reason for Implant	6.29	5.57	.10	1.13	.262
FPAS[b] Total Score	.91	.16	.52	5.74	<.001***
Model Four Summary	F (6, 87) = 10.66	*p* = <.001***	R^2 = .42	adjusted R^2 = .38	

Note. N=100. Dependent Variable: Psychological Well-being Scale (PWB) Total Score. Predictors: (Constant), Age, Gender, Number of Comorbidities, [a] Implantable Cardioverter Defibrillator (ICD) Shocks, Reason for Implant, [b] Florida Patient Acceptance Survey (FPAS) Total Score.

*p<.05. **p<.01. ***p<.001.

Regression Model Five: Social Facilitation.

Adjusting for age and gender, the variable to assess social facilitation, MSPSS "Total Score", was added to regression model five to examine associations with psychosocial well-being. A multiple regression was calculated to predict psychosocial well-being based on the variables. The model significantly predicted 39% of the variance in psychosocial well-being, F (3, 92) = 21.67, p = <.001 (Table 4.10). MSPSS "Total Score" (p = <.001) and "Age" (p = .013) positively predicted psychosocial well-being. Participant's predicted psychosocial well-being is equal to 99.72 + 14.20 (MSPSS Total Score) + 0.45 (Age), where MSPSS "Total Score" is coded positively by score and "Age" is coded by number of years. Participants' psychosocial well-being increased by 14.20 for each point increase in MSPSS "Total Score" and increased by 0.45 for each increase in year of age. Both MSPSS "Total Score" and "Age" were significant predictors of psychosocial well-being. "Gender" was not a significant predictor of psychosocial well-being.

Table 4.10

Regression of Associations of Social Facilitation with Psychosocial Well-Being

Variable	B	*SE* B	*β*	*t*	*p*
(Constant)	99.72	20.36		4.90	<.001***
Age	.45	.18	.22	2.54	.013*
Gender	-5.41	5.72	-.08	-.95	.346
MSPSS[a] Total Score	14.20	1.98	.58	7.19	<.001***
Model Five Summary	F (3, 92) = 21.67	*p* = <.001***	R^2 = .41	adjusted R^2 = .39	

Note. N=100. Dependent Variable: Psychological Well-being Scale (PWB) Total Score.

Predictors: (Constant), Age, Gender, [a] Multidimensional Scale of Perceived Social Support (MSPSS) Total Score.

*p<.05. **p<.01. ***p<.001.

Manuscript Three

Psychosocial Well-Being of Individuals Living with an Implantable Cardioverter

Abstract

Background: An Implantable Cardioverter Defibrillator (ICD) is an effective intervention for individuals at risk for sudden cardiac arrest. Uncertainty and social facilitation impact individuals living with an ICD's psychosocial well-being.

Objective: This study aimed to examine the associations between uncertainty and social facilitation with the psychosocial well-being of adults living with an ICD.

Methods: This study employed a quantitative exploratory-descriptive design with a convenience sample of participants (N=100), 71% women. A 91-item survey included measures of patient characteristics and the Florida Patient Acceptance Survey (FPAS) to assess uncertainty, the Multidimensional Scale of Perceived Social Support (MSPSS) to assess social facilitation, and the Psychological Well-Being Scale (PWB) to assess psychosocial well-being.

Results: Psychosocial well-being (n=96) was predicted by "ICD shocks" (n=100, B = -7.48, p = .004), "Reason for Implant" (n=100, B = 12.43, p = .05), "Device-Related Distress" (n=100, B =.61, p = <.001), "Return to Life" (n= 100, B =.68, p = .004), "Overall ICD Acceptance" (n=100, B =.91, p = <.001), and "Social Facilitation" (n= 100, B = 14.20, p = <.001). Age (n=100) significantly predicted psychosocial well-being, but gender was not significant.

Conclusions: This study demonstrates the importance of identifying factors influencing psychosocial well-being for underserved groups with an ICD. A biopsychosocial approach to care provision is needed to support adjustment to the device.

Key Words: Implantable Cardioverter Defibrillator, Psychosocial Well- Being, Uncertainty, Social Facilitation

An Implantable Cardioverter Defibrillator (ICD) is an effective intervention for individuals with chronic cardiovascular conditions at risk for SCA (Al-Khatib et al., 2018; Moss et al., 1996; National Institutes of Health [NIH], 2021; Zipes et al., 2006). Historically, ICDs were implanted for secondary prevention as a last resort following a SCA (Klein & Nisam, 2015). Continuous improvements in technology of the device, leads, therapies, and programming have occurred since the first ICD was implanted 40 years ago (Al-Khatib et al., 2018; Zipes et al., 2006). The advancement of ICD technology improved delivery of therapies and ease of implant. Subsequent studies showed efficacy in expansion of implant criteria to reduce Sudden Cardiac Death (SCD). For this reason, primary prevention criteria for those at risk of SCA, were adopted in the early 2000s (Zipes et al., 2006). The new criteria influenced a rapid and sustained rise in annual implant numbers up to 300,000 within the United States (Al-Khatib et al., 2018). A mandatory national ICD registry was established in the United States in 2005 to monitor data, including demographics, on ICD implants. From 2005 to 2011, the registry logged over 850,000 ICD cases; of these cases, approximately 72% were men and 28% women (Kremers et al., 2013).

Rationale

Introduction to an ICD occurs during times of stress when individuals face life events that highlight mortality and risk for SCA. The experiences of living with an ICD may bring about a stressed response marked by fear, hopelessness, or horror (Ford et al., 2013; Briere & Scott, 2015). Responses to stressful events are dependent on influencing factors (Federal Interagency Forum on Aging-Related Statistics [FIFAS], 2016), including individual patient characteristics, mortality, presence of comorbidities, assessment of health, and psychological health. Having higher levels of psychosocial well-being plays a pivotal role in adjusting to the ICD implant.

Conceptual framework

Lifestyle changes following ICD placement are potentially challenging for individuals, bringing uncertainty, and undermining a sense of normalcy (Flanagan et al., 2010; Flemme et al., 2011). The conceptual framework for this study, entitled *Impact of Uncertainty on Psychosocial Well-Being,* was constructed to identify potential underlying factors related to uncertainty that may influence an individual's ability to adjust to their ICD implant, and maintain their psychosocial well-being (Figure 1). Conceptualizing the ICD experience utilizing the framework identifies feelings of control and emotional stability for individuals living with an ICD (Leventhal et al., 1984). The framework provides an avenue for exploring the independent variables of uncertainty and social facilitation and their influence on the dependent variable of psychosocial well-being.

Purpose

Primary aims of this study are to examine the associations between knowledge, severity of cardiovascular condition, individual stress appraisal, acceptance of the ICD, and social facilitation with psychosocial well-being among adults living with an ICD. A hypothesis was identified for the main research question. Controlling for age and gender, knowledge of the ICD, severity of cardiovascular condition, individual stress appraisal, acceptance of the ICD, and social facilitation will predict psychosocial well-being in adults with an ICD. The purpose of this study is to examine how an individual's perceptions of living with an ICD impacts their psychosocial well-being.

Methods

A quantitative exploratory-descriptive design was utilized to identify associations between potential factors related to uncertainty and social facilitation influencing individual psychosocial well-being (Polit & Beck, 2018).

Sampling

A convenience sample (N=100) was obtained from various locations within the United States including ambulatory clinics and social media. Recruitment was conducted using a flyer social media, and word of mouth. Inclusion criteria for the study consisted of (a) implant of ICD longer than 3 months, (b) adults over 18 years, and (c) ability to speak, read and write in English. Exclusion criteria consist of (a) current hospitalization, (b) impaired cognition, and (c) international (Polit & Beck, 2017; Yamiz, 2013). Efforts were made to ensure the participants were demographically diverse, however, given the size of the sample, diversity was limited (Polit & Beck, 2017; Shadish, Cook, & Campbell, 2002).

Data Collection

Approval was obtained for the study from the University of Wisconsin-Milwaukee Institutional Review Board (IRB), study number 21.318, as the main IRB. Additional IRB approval was obtained from the University of Minnesota IRB, study number 00014109, as a recruitment site. Once IRB approval was be obtained recruitment and enrollment commenced. Voluntary participation in the study was conducted virtually over the phone or zoom. Participants were screened for inclusion in the study and verbal informed consent was obtained from interested parties. Data was obtained, de-identified, and entered into Qualtrics computer software on the University of Wisconsin-Milwaukee server using a password-protected computer.

Measures

Data was collected utilizing measurement instruments to answer the research questions and describe the associations among the variables. The measurement instruments have shown good reliability and validity in other studies. The patient characteristics form was used to measure the demographics, life changes, and perception of severity of the condition that influences an individual's ability to adjust to an ICD. Stress appraisal measures emotional stability and demands to change lifestyle in reaction to a living with the ICD and acceptance is evidenced by returning to physical and psychosocial activities post implant. The Florida Patient Acceptance Scale (FPAS) (Cronbach's alpha .860) was used to measure concepts under the umbrella of uncertainty. Social Facilitation was measured by the presence and influence of support, and the degree of collaboration with supportive networks to promote change using the Multidimensional Scale of Perceived Social Support (MSPSS) (Cronbach's alpha .947). Well-being is a subjective construct defined through identification of interactions between social, psychological, and health-related dimensions (Diener et al., 1999). The 42-item Psychological Wellbeing (PWB) (Cronbach's alpha .940) scale was be used to measure psychosocial well-being. PWB includes seven items for each of the six subgroups within the scale distinguished as (a) autonomy, (b) environmental mastery, (c) personal growth, (d) positive relations with others, (e) purpose in life, and (f) self-acceptance.

Analysis

Data analysis was conducted using the latest version of SPSS ® software. The study aims and main research question were analyzed using descriptive statistics, Pearson's correlations, and multiple regression. The analysis examined associations between the independent variables,

levels of knowledge, individual stress appraisal, acceptance, social facilitation, with psychosocial well-being (Polit & Beck, 2017).

Results

Demographic and Clinical Characteristics of Participants

A majority of the individuals living with an ICD who participated in the study (*N*=100) were women (71%), less than 65 years of age (76%), White (87%), and married (54%) (Table 4.1). Most male participants (48%) were over 65 years and generally older than the women in this study. All participants had a minimum of a high school diploma/GED, with the majority (76%) having completed a college degree. More males (69%) completed education at the bachelor level or higher than females (52%). Participants with a higher education reported an increased annual salary (r = .424, p = <.001). Annual reported incomes varied, with men having a higher annual salary than women. Twenty-one percent of the women reported annual incomes of less than $30,000. The majority of the participants (66%) were non-smokers living independently (87%), who exercised regularly (84%) at a mild (40%) or moderate (38%) level. Job changes for participants, including retirement, increased with age (r = .382, p = <.001). A high number of participants reported being obese (46%) regardless of gender, with BMIs ranging from 16.6 to 50.6 and a mean of 30.3 (*SD*=7.1). A majority (64%) of participants reported engagement in at least one or more groups for support or activities.

Knowledge

Participants reported understanding the ICD and how it works, with a high FPAS knowledge mean score of 8 (*SD*=1.8) (Table 4.3). Participants who had received multiple ICDs through subsequent replacements reported greater knowledge and understanding about the ICD (r = .345, p = <.001), suggesting that having multiple ICDs increases individual's understanding

of how the device works and what it does for them. Participants with broken wires tended to be less knowledgeable about the ICD (r = -.212, p = .034). Knowledge had no significant correlations with other variables in the study.

Participant's Condition

Descriptive findings on participant demographic and clinical characteristics provide an overview of the general health and condition of the participants. The severity of the condition was measured by the number of comorbidities, criterion for placing the ICD implant, and the prevalence of ICD shocks.

Comorbidities

A majority of the participants reported having at least one comorbidity (89%), with higher numbers of comorbidities correlated with older age (r = .230, p = .022), and higher BMI (r = .230, p = .022). Participants with a higher number of cardiovascular comorbidities were more likely to have a weakened heart muscle (r = .644, p = <.001), atrial fibrillation (r = .558, p = <.001), congestive heart failure (r = .573, p = <.001), or hypertension (r = .380 p = <.001). Individuals with a genetic condition reported fewer cardiovascular comorbidities (r = .281, p = <.001) were younger (r = .226, p = .024), and female. Participants who reported a weakened heart muscle often experienced congestive heart failure (r = 0.507; p = <0.001) or atrial fibrillation (r = 0.306; p = 0.002).

Reason for ICD Implant

A majority of participants are living with their first ICD (62%). Most participants (61%) had their original device implanted following a life-threatening arrhythmia or cardiac arrest, while 39% received the ICD implant due to risk of SCA. More individuals implanted for secondary prevention were college educated (r = .232, p = .020), had annual income over

$50,000 ($r$ = .313, p = .002), and engaged in more intense physical activity (r = .206, p = .040). The presence of a weakened heart muscle (r = 0.285, p = 0.004) and congestive heart failure (r = 0.438, p = <0.001) more often correlated with receiving an ICD for secondary prevention.

ICD Shocks

Over a third of the participants (37%) reported one or more ICD shocks, and half of those individuals (18%) experienced multiple shocks in one day. Higher numbers of ICD shocks were correlated with a history of more procedures (r = .323, p = <.001), complications (r = .236, p = .018), and multiple shocks in a day (r = .520, p = .001). Shocks for non-life-threatening reasons occurred with a higher number of device procedures (r = .525, p = <.001) or a higher number of ICD complications (r = .622, p = <.001). A significant number of participants with inappropriate shocks experienced a shock storm of multiple shocks in one day (r = .580, p = .012).

Stress Appraisal

Scores for device-related distress (77, SD = 21.7) indicate varied experiences among participants in managing stress (Table 4.3). Participants who were younger (r = .384, p = <.001), had less income (r = .270, p = .007), a job loss or change (r = .207, p = .039), or restricted driving (r = .212, p = .034) tended to have more device-related distress. Conditions that correlated with participants having more device-related stress include mental health (r = .245, p = .014), genetic conditions (r = .250, p =.012), and congestive heart failure (r = .205, p = .041). Although participants implanted for secondary prevention tended to have more device-related stress than those implanted for primary prevention (r = .211, p = .035), ICD shocks and complications did not directly correlate. The majority of participants did not feel depressed (61%) when thinking about the device. Most participants had a positive view of themselves, with

a FPAS subscale body image mean of 87 (*SD*=21.3) (Table 4.3). Younger participants (r = .479, p = <.001) reported a significantly lower body image.

Acceptance

Participants acceptance of living with their ICD was measured by their ability to return to life and positively appraise the ICD. Higher scores reflect the participant's ability to return to their life experienced prior to receiving an ICD and expressing a positive view of the device.

Return to Life

Scores on return to life (73, *SD*=27.6) indicate varied life experiences living with an ICD (Table 4.3), but a majority reported returning to work (77%) and physical activity (71%). Participants with higher levels of college education (r = .332; p = <.001) and income (r = .347; p = <.001) reported an easier time adjusting to life with the ICD. Participants with more comorbidities (r = .289; p = .004), a weakened heart muscle (r = .257; p = .010), congestive heart failure (r = .419; p = <.001), a mental health condition (r = .237; p = .018) reported less ability to return to life after the ICD. Independence with activities of daily living (r = .537; p = <.001), attending groups (r = .266; p = .008), engaging in physical activity (r = .384; p = <.001), or ability to drive (r = .298; p = .003) enhanced adjustment to life with an ICD.

Positive Appraisal

Most participants had a positive attitude about living with the ICD, with a positive appraisal mean of 86 (*SD*=22.5). Most participants reported the positives of the ICD outweighed the negatives (86%), felt safer with an ICD (82%), and would receive the ICD again (83%). Experiencing more complications (r = .266; p = <.008), including a broken lead (r = .221; p = .027), infection (r = .252; p = .012), or inappropriate ICD shocks (r = .218; p = .029) negatively impacted the ability to remain optimistic about the ICD.

Social Facilitation

Most participants (78%) had moderate to high total social facilitation scores, with a mean of 5.9 (*SD*=1.8), indicating moderate to high levels of support from others (Table 4.3). Male and female participants had similar social support from partners, family, or friends (Table 4.4). Participants reported more support from a partner (mean = 6.3, *SD*=1.3), than family (mean = 5.7, *SD* = 1.5) or friends (mean = 5.7, *SD* = 1.5). Participants with a higher income level reported higher levels of education (r = .424; p = <0.001) and support from others (r = .222, p = .026). Those with annual incomes over $50,000 engaged in various groups (r = .199, p = .048) for support and activities outside their neighborhoods, but individuals with annual income less than $50,000 sought support from neighborhood groups (r = .298; p = .003). Participants with congestive heart failure (r = .270, p = .007) felt supported by family and friends, whereas individuals needing help with activities of daily living (r = .254, p = .011) reported less support.

Psychological Well-Being

Most participants (71%) reported moderate to high levels of psychosocial well-being, with a mean PWB total score of 199 (*SD*=30.2). More female participants reported lower psychological well-being (32%) than male participants (11%) (r = .206, p = .044). Older participants (r = .243, p = .015) with more understanding of the ICD (r =.207, p =.039) reported higher perceptions of autonomy. Psychosocial well-being was positively increased by living independently (r = .402, p = <.001), engaging in physical activity (r = .418, p = <.001), having a college education (r = .268, p = .008), or higher annual income (r = .369, p = <.001). Mastering the environment increased with age (r = .405, p = <.001), higher education (r = .220, p = .030), higher annual income (r = .377, p = <.001), and more physical activity (r = .394, p = <.001).

Participants with higher BMI (r = .308, p = .002), a mental health condition (r = .530, p = <.001), or congestive heart failure (r = .333, p = <.001) reported lower psychosocial well-being. Participants with a genetic condition (r = .289, p = .004) or congestive heart failure (r = .297, p = .003) reported more difficulty mastering their environment. Participants who received the ICD after a cardiac arrest or life-threatening arrhythmia reported higher levels of psychosocial well-being (r = .232, p = .023), sense of self (r = .269, p = .007), and personal growth (r = .271, p = .007) compared implant for precautionary measures. Conversely, participants who received a shock (r = .231, p = .024) or lost driving privileges (r = .230, p = .024) reported lower psychosocial well-being in part due to feeling less control over their environment. Participants congestive heart failure (r = .428, p = <.001) who could not maintain a healthy weight (r = .324, p = .001) or live independently (r = .318, p = .001) reported less self-acceptance (r = .293, p = .003) and ability to grow personally (r = .241, p = .016).

A majority of participants have a sense of direction in life (72%) and remain open to new experiences that improve their growth (82%) but struggle with the change in familiar patterns (62%). Participants with higher education (r = .299, p = .003), higher annual income (r = .315, p = .002), attending more groups (r = .203, p = .044), and engaging in more physical activity (r = .200, p =.047) reported improvements in personal growth. Most participants reported feeling positive and confident about themselves (67%) and how their lives turned out (53%). Self-acceptance improved for participants with age (r = .276, p = .005), higher education (r = .223, p = .026), higher annual income (r = .385, p = <.001), and engagement in physical activity (r = .331, p = <.001). Physically active (r = .307, p =.002) participants with higher income (r = .267, p = .007) and a positive view of their contribution (81%) maintained close relationships (65%) that were engaging (88%) and trustworthy (85%). Attending more groups

(r = .254, p = .012) positively influenced psychosocial well-being and building of positive relationships (r = .257, p = .010), especially at work (r = .226, p = .024). Relationship status was negatively affected by the inability to manage ADLs (r = .380, p = <.001), drive (r = .201, p = .045), or maintain a healthy weight (r = .224, p = .025).

Engaging in physical activity (r = .358, p = <.001), group activities (r = .253, p = .011), work groups (r = .219, p = .028), higher education (r = .253, p = .011), or higher paying jobs (r = .322, p = .001) strengthened perceptions of purpose in life. Participants with an increased number of comorbidities (r = -.317, p = .001) or higher BMI (r = .313, p = .002) reported diminished purpose in life and those unable to manage their ADLs (r = .375, p = <.001) experienced less personal growth.

Multiple regression

A multiple regression was calculated to predict psychosocial well-being based on the variables. Psychosocial well-being (n=96) was predicted by ICD shocks (n=100, B = -7.48, p = .004), reason for implant (n=100, B = 12.43, p = .05), device-related distress (n=100, B =.61, p = <.001), return to life (n= 100, B = -7.48, p = .004), overall ICD acceptance (n=100, B =.91, p = <.001), and social facilitation (n= 100, B = 14.20, p = <.001) in the regression models. Age (n=100) significantly predicted psychosocial well-being, but gender was not significant. Number of comorbidities, and knowledge, body image, and positive appraisal were not significant predictors of psychosocial well-being. Participant psychological well-being scores decreased by 7.48 for each increase in number of shocks, increased by 0.48 for each increase in year of age, increased 12.43 points for secondary prevention reason for implant, decreased by 0.61 points for each point of increase in device-related distress, increased by 0.68 for each point

increase in return to life scores, and increased by 14.20 for each point increase in social facilitation scores.

Discussion

Positive well-being is associated with adults experiencing improved cardiovascular health, including decreased morbidity and mortality rates (Centers for Disease Control and Prevention [CDC], 2020). Uncertainty is more likely to occur for individuals when they are reminded of their mortality. Individuals adjusting to life with an ICD must deal with the dread of shocks and risk for SCA. When fearing SCA, individuals living with an ICD often view the device as a lifeline to survival (Manuel & Brunger, 2016). The ability to adjust to life with an ICD depends on uncertainty-related characteristics, including condition, stress appraisal, and acceptance of an ICD, which are associated with their social facilitation and psychosocial well-being experiences.

Overall, participants reported a moderate to strong sense of psychological well-being. The majority of participants in this study were female (n=71) and White (n=87), with few participants (n=13) representing diverse race/ethnic backgrounds. Participants represented ages from 21 to 84, with the majority of female participants under the age of 65 years (n=54) and only half of the male participants (n=14) over 65 years of age. Conversely, samples in studies within the United States are often homogenous, with the majority being White, educated, married men (81%) (Kremers et al., 2013; Mauro, 2010), over the age of 65 years (Kremers et al., 2013). Therefore, this study provides information on an understudied population within the United States of younger and mostly female participants living with their first ICD. Resources such as having a college education and more disposable income increased the ability for participants in this study to adjust to living with the ICD. Male participants in this study were in a higher

income bracket that afforded access to resources and socioeconomic stability. However, female participants had lower seriocomic status and perceived psychosocial well-being than males, which socioeconomic differences may influence. Similarly, Jakub (2018) conducted a gender study focused on living with ICDs and reported that participant stage in life and age influenced the adjustment to the ICD more than gender.

The participants in this study reported similar findings to Morken et al. (2010), that over time and with experience living with an ICD, individuals become more independent and autonomous with their ability to self-direct their decisions, regulate their behavior, and adapt to circumstances. Older individuals in this study accepted the ICD more readily as they had more life experiences to draw from when adapting to new situations. Therefore, it is not surprising that with age, participants in this study had a greater sense of mastering their environment and ability to manage daily life with the ICD. This study found that a debilitating condition, lack of financial resources, and loss of driving privileges decreased independence for participants at any age and negatively impacted their psychosocial well-being.

Knowledge

Knowledge was not a significant predictor of psychosocial well-being in this study, but individual autonomy improved with more knowledge. Wilson et al. (2013) reported that having increased knowledge of how the ICD works improves acceptance of the device. A majority of participants living with their first ICD indicated they understood how the device works to prevent SCA; knowledge increased further with subsequent ICD implants. Investigators studying ICD acceptance reported that minimal changes to adjustment occur after the first year of living with an ICD (Pedersen et al., 2013), which may account for knowledge not being a predictor of psychosocial well-being in this study. Previous research indicates that having questions answered

and knowledge about the ICD reduces individual's anxiety about the future (Berg et al., 2017). A broken wire often leads to ICD shocks, which is a stressful and emergent event. In this study, participants with a broken wire reported less knowledge about the ICD than those with other complications. Participants in this study reported unique experiences requiring ongoing assessment for individualized care and education. An individual's knowledge of complications inherent in living with ICD is dependent on their experiences, impact on health, and prior education. A study on octogenarians living with an ICD supports health professionals' provision of general education related to living with an ICD (Wising et al., 2022).

Conditions Necessitating the ICD

Participants in this study's reason for receiving an ICD implant, whether primary or secondary prevention, and subsequent ICD shocks predicted their psychosocial well-being. Participant's perceptions of decreased well-being correlated with their chronic condition in this study but were not significant predictors. An individual's ability to manage a chronic condition is influenced by their current health and experiences with the condition, life situation, personal beliefs, and social support (Anudulv et al., 2012). Participants of this study had various chronic conditions which posed a risk for requiring the ICD implant. A majority of the participants had at least one comorbidity and were overweight, placing them at risk for requiring complex management. Prior studies do reveal that females receiving an ICD for primary prevention are older, have more comorbidities, are at risk for more complications, and therefore have less mortality benefit from the ICD (Han & Russo, 2022). In this study the additive effects of multiple comorbidities did not predict impact psychosocial well-being unless it led to a debilitating physical condition affecting daily life.

Participants in this study who experienced cardiac arrest viewed the ICD optimistically as a necessary part of their future life. Optimism and hope for the future reinforce resiliency when facing stressful situations (Briere & Scott, 2015). ICD implants for secondary prevention occurred more often for participants with a severe condition, including a weakened heart muscle or congestive heart failure. Presciutti et al. (2019) conducted a study of cardiac arrest survivors and found that ICD recipients who received an ICD for secondary prevention recovered well after the implant unless they had a history of depression. A higher percentage of participants in this study were implanted for secondary prevention and had increased income, education, abd physical activity, unlike Presciutti et al. (2019) reported high levels of psychosocial well-being. Higher socioeconomic stability enabled participants to access resources to assist in adjustment to living with their ICD, which may have contributed to their optimism and positive appraisals of having a second chance in life.

Mauro (2010) conducted a study on the impact of ICD shock reported the unpredictability and uncertainty of the shocks over time can cause accumulating fear of the device triggering, creating a disabling loss of control. Participants in Mauro's (2010) study also reported that individual's perceptions of safety and stability altered over time and were diminished due to ICD shocks. Investigators have identified that individual's experience ambiguity and vulnerability when living with an ICD due to underlying heart disease and unpredictability of potential treatment via shocks (Dehghanadeh et al., 2018; Ooi, 2018; Pasyar et al., 2015). ICD shocks undermined participant's sense of control over their environment in this study, as fear of the unknown decreased psychosocial well-being. Participants who received shocks more often also had multiple shocks, inappropriate shocks, higher number of procedures, and more complications. The combination of an ICD shock with other exacerbators may have

influenced participants lower level of psychosocial well-being. Thylén et al. (2016) reported that in a large quantitative study of over 3000 participants, individuals had more ICD-related concerns than the shock itself. Investigators also reported that most ICD recipients who did not receive shocks did not report stressors or concerns with daily living (Flemme, Johansson et al., 2012). Similarly, in this study, participants who never received a shock reported less stress, higher acceptance of the device, and viewed the ICD as a lifeline. Although circumstances with shocks may affect individuals, resilience and adaptation to living with an ICD improves their overall response when a shock does occur.

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Stress Appraisal

Device-related distress was a predictor of individuals psychosocial well-being in this study, but body image was not. Participants who had higher levels of distress due to their ICD had lower levels of psychosocial well-being. Traumatic medical experiences that the individual cannot control and perceives as negative influences perceptions of well-being (Briere & Scott,

2015; Carlson & Dalenberg, 2000). Nationally, approximately 30% of ICD recipients experience anxiety and 20% depression related to ICD implant, and risk for pathological anxiety increased with the presence of shocks (Redhead et al, 2010). Low levels of depression or anxiety were reported in this study, with a small percentage reporting pathological stress as they shared avoiding things they enjoy (15%) and finding it hard to function with the device (14%). In this study the presence of device related distress and signs of maladaptation to the ICD correlated with lower levels of psychosocial well-being. Amongst women, researchers reported an increased risk for anxiety from living with an ICD (Flemme, Johansson, et al., 2012; Wilson et al., 2013). Though not gender specific, Pedersen et al. (2013) found that individuals with weakened heart muscles or atrial fibrillation were at increased risk for anxiety (Pedersen et al., 2013).

Presciutti et al. (2019) conducted a qualitative study on the long-term perceptions of individuals living with an ICD. The investigators found that after cardiac arrest individuals reported depression, which significantly influenced their adjustment to an ICD overtime. The presence of depression, anxiety, and higher mortality burden decreased HRQoL for individuals living with an ICD in a study by Miller et al. (2019). Similarly, in this study, participants who experienced higher mortality after implant of the ICD for secondary prevention, experienced less feeling of control over their environment and more distress. Individuals in several studies who reported a history of anxiety, depression, or adverse psychological functioning before cardiovascular surgery had risk for concerns after surgery with mental health, lower personal growth or control (Hammash et al., 2019; Oxlad & Wade, 2008).

Ability to overcome hardships, disappointments, and manage circumstances related to living with an ICD impacts the individual's adjustment to the ICD. Participants in this study who

experienced a sense of loss or stressful situations, such as restriction of driving or ICD shocks that can impact everyday life, reported higher levels of device related distress. Patients with ICD's who are negative may experience increased distress levels (McCaig et al., 2014). In this study, younger participants living with an ICD due to a genetic condition had more device-related distress, their fear of the unknown may be the reason for the added stress. Although most participants in this study had a positive self-image, the younger participants struggled were more at risk for a negative self-image. Larimer et al. (2016) conducted a qualitative study on the impact of younger recipients living with an ICD and found they had more body image concerns, fears about the future, and less support from others. In this study, participants who attended church groups reported higher levels of body image, which may be related to social support.

Acceptance

Participant's return to life significantly predicted higher levels of psychosocial well-being in this study, whereas positive appraisal of the ICD did not. Participants in this study had resilience and a positive attitude toward living with an ICD, reported as high levels of personal growth and acceptance of their circumstances. The findings in this study are consistent with other studies that reported acceptance and positive appraisal of the ICD (Fumagalli et al., 2018; Haugaa et al., 2018; Wilson et al., 2013). Participants not impacted by the device daily reported more acceptance of the ICD. Conversely, those participants with a condition that impacted their daily life, including a weakened heart muscle, congestive heart failure, ICD complications, or a mental health condition, had a negative appraisal and less acceptance. Similarly, individuals in a study conducted by Ooi et al. (2016) who had a pessimistic outlook driven by fear, anxiety, ICD shocks, dependence, and loss of intimacy had less acceptance of the ICD. Several studies reported that individuals living with an ICD face ambivalence of acceptance due to attempting to

remain optimistic about the ICD while experiencing fear and anxiety related to potential shocks (Dehghanadeh et al., 2018; Ooi et al., 2018).

Flemme et al. (2011) conducted a study on ICD recipients that found individuals utilize self-strategies to process life changes and strengthen acceptance, including building daily routines, strengthening optimism through distraction, regaining hope for the future, and formulating goals. The majority of participants in this study set goals and remained engaged in activities, which correlated with a sense of direction and meaning in life. Those participants with accessibility to socioeconomic resources due to higher incomes, education, and social support, more readily re-engaged in life and viewed the ICD as an opportunity for personal growth. In this study, group attendance improved acceptance and the ability to return to life. Participants may be attempting to normalize their life and seek out distractions from living with the ICD through engagement in activities of everyday living that occur when attending sports, neighborhood, or church groups. As in a study conducted by Flemme, Johansson et al. (2012), participants in this study with mastery over their environment reported accepting and living well with the ICD.

Social Facilitation.

Social facilitation significantly predicated psychosocial well-being in this study. Multiple studies report negative buffering experiences with social support (Flurr et al., 2013; Hazelton et al.,2009; Tehee et al., 2017). In this study, maintaining positive relationships correlated with increased levels of psychosocial well-being. Participants who reported having intimate and trusting relationships with a partner, family, or friends had higher levels of psychosocial well-being. The participants in this study reported that the most intimate and impactful support was from a partner or special person in their lives. Even though this study identified the impact of

these intimate partners, another study reported that ICD recipients who expressed fear of hypervigilance from spouses over health status and an uncertain future isolated themselves from their families (Fluur et al., 2013; Humphreys et al., 2016). A study on partners reported that engaging partners in care and having interactive and trusting relationship improves the adjustment of the individuals living with the ICD (Dougherty et al., 2019). Although participants in this study reported family and friends as positive support for adjusting to life with an ICD, some participants were more hesitant to share sensitive needs outside their intimate partners. Other studies on individuals living with an ICD or chronic condition report that the occurrence of altered family roles necessitates flexibility to fit the needs of the individual and the changing roles (Arestedt et al., 2014; Fluur et al., 2013; Hazelton et al. (2009). The socioeconomic status of participants in this study influenced the level of positive support they reported; participants with higher status had improved psychosocial well-being. Participants with a higher socioeconomic status reported engagement in an increased variety of social networks. In contrast, participants with a lower status limited their engagement with neighborhood networks, possibly due to cost, transportation, or lack of access to resources. Participants with congestive heart failure reported higher levels of support, possibly due to the nature of the disease and varied levels of dependence and reliance on others as the disease progresses. In contrast, those who reported needing more help with ADLs reported feeling less supported by others. In a study on older adults living with chronic conditions, the presence of social support showed a reduction in the perception of events as traumatic (Tehee et al., 2017)

Limitations

Policies enacted during the COVID-19 pandemic made recruiting from traditional sources such as health systems and doctors' offices difficult. This study had a low enrollment of

diverse races or ethnicities, and the lack of diversity limits the dissemination of the findings broadly to the larger population. Reliance on self-report in this study limits data from the study to individual subjective perceptions of health and well-being at a particular moment and are not measurable physiological levels of health. Finally, the study design assessed potential associations between the variables and was limited in finding causality between the variables.

Conclusion

The majority of participants in this study reported moderate to high levels of psychosocial well-being. The reason the ICD was implanted, experiencing ICD shocks or stress related to the ICD, acceptance of the ICD and social facilitation were predictors of change in psychosocial well-being. The age of participants was predictive of psychosocial well-being, implicating a potential relationship with different stages in life. Interestingly, this study enrolled a majority of women and findings indicate women and men have similar responses to living with an ICD.

Chapter Summary

This chapter provided an overview of the results of this quantitative exploratory-descriptive design to identify associations among the study variables. Results include descriptive statistics and multiple regression to assess relationships between the variables and predictions for the dependent variable. The research questions were explored through data analysis, and the results of the multiple regressions supported the hypothesis. More women are represented in this study than men. Participants from all age groups are represented in the study. Variables within the models for the severity of condition, stress appraisal and acceptance, overall uncertainty, and social facilitation were significant predictors of psychosocial well-being. Age significantly predicted psychosocial well-being with regression models for the severity of condition, acceptance, and social facilitation. Manuscript Three reviews the findings of the study and the significance of the findings to psychosocial well-being.

Chapter Five: Discussion

A summary of the main study findings is presented in this chapter including a review of the relationships between variables and research questions. Findings are interpreted and explored for similarities and differences with results from previous studies. Implications and limitations of the study are discussed, concluding with a final summary.

Summary of the Main Study Findings

This study examines the ways in which the perceptions of uncertainty and social facilitation in adults living with an ICD impact their psychosocial well-being. Findings on associations between psychosocial well-being, uncertainty, and social facilitation are discussed. Uncertainty was examined through a measurement of knowledge and severity of condition, stress appraisal, and acceptance of the ICD. For this study, age was a significant predictor of psychosocial well-being in relation to the severity of condition, acceptance of the device, and support for social facilitation. ICD shocks, the reason for the ICD implant, device-related distress, participants' ability to return to their lives, and social facilitation were significant predictors of psychosocial well-being. Participants gender, number of comorbidities, knowledge about the device, body image, positive appraisal, and ability to return to everyday sex life were not predictors of psychosocial well-being. The findings from the study support the hypothesis that uncertainty and social support predict an individual's psychosocial well-being.

Relationship Between Variables

Overall, participants reported a moderate to strong sense of psychological well-being. The majority of participants in this study were female (n=71) and White (n=87), with few participants (n=13) representing diverse race/ethnic backgrounds. Participants represented ages

from 21 to 84, with the majority of female participants under the age of 65 years (n=54) and only half of the male participants (n=14) over 65 years of age. Conversely, samples in studies within the United States are often homogenous, with the majority being White, educated, married men (81%) (Kremers et al., 2013; Mauro, 2010), over the age of 65 years (Kremers et al., 2013). Therefore, this study provides information on an understudied population within the United States of younger and mostly female participants living with their first ICD. Resources such as having a college education and more disposable income increased the ability for participants in this study to adjust to living with the ICD. Male participants in this study were in a higher income bracket that afforded access to resources and socioeconomic stability. However, female participants had lower seriocomic status and perceived psychosocial well-being than males, which socioeconomic differences may influence. Similarly, Jakub (2018) conducted a gender study focused on living with ICDs and reported that participant stage in life and age influenced the adjustment to the ICD more than gender.

The participants in this study reported similar findings to Morken et al. (2010), who found that over time and with experience living with an ICD, individuals become more independent and autonomous with their ability to self-direct their decisions, regulate their behavior, and adapt to circumstances. Older individuals in this study accepted the ICD more readily as they had more life experiences to draw from when adapting to new situations. Therefore, it is not surprising that with age, participants in this study had a greater sense of mastering their environment and ability to manage daily life with the ICD. This study found that a debilitating condition, lack of financial resources, and loss of driving privileges decreased independence for participants at any age and negatively impacted their psychosocial well-being.

Knowledge

Knowledge was not a significant predictor of psychosocial well-being in this study, but individual autonomy improved with more knowledge. Wilson et al. (2013) reported that having increased knowledge of how the ICD works improves acceptance of the device. A majority of participants living with their first ICD indicated they understood how the device works to prevent SCA; knowledge increased further with subsequent ICD implants. Investigators studying ICD acceptance reported that minimal changes to adjustment occur after the first year of living with an ICD (Pedersen et al., 2013), which may account for knowledge not being a predictor of psychosocial well-being in this study. Previous research indicates that having questions answered and knowledge about the ICD reduces individual's anxiety about the future (Berg et al., 2017). A broken wire often leads to ICD shocks, which is a stressful and emergent event. In this study, participants with a broken wire reported less knowledge about the ICD than those with other complications. An individual's knowledge of complications inherent in living with ICD is dependent on their experiences, impact on health, and prior education. A study on octogenarians living with an ICD supports health professionals' provision of general education related to living with an ICD, including shocks, electromagnetic interference, and potential complications (Wising et al., 2022). Participants in this study reported unique experiences requiring ongoing assessment for individualized care and education. Concerns for end-of-life education were less prevalent in this study, possibly due to most participants being younger and living with the ICD for a short time.

Conditions necessitating the ICD

Participants in this study's reason for receiving an ICD implant, whether primary or secondary prevention, and subsequent ICD shocks predicted their psychosocial well-being.

Participant's perceptions of decreased well-being correlated with their chronic condition in this study but were not significant predictors. An individual's ability to manage a chronic condition is influenced by their current health and experiences with the condition, life situation, personal beliefs, and social support (Anudulv et al., 2012). Participants of this study had various chronic conditions which posed a risk for requiring the ICD implant. A majority of the participants had at least one comorbidity and were overweight, placing them at risk for requiring complex management. This study found that a debilitating condition, lack of financial resources, and loss of driving privileges decreased independence for participants any age and negatively impacted psychosocial well-being. However, the additive effects of multiple comorbidities did not predict impact psychosocial well-being.

Participants in this study who experienced cardiac arrest viewed the ICD optimistically as a necessary part of their future. Optimism and hope for the future reinforce resiliency when facing stressful situations (Briere & Scott, 2015). ICD implants for secondary prevention occurred more often for participants with a severe condition, including a weakened heart muscle or congestive heart failure. Presciutti et al. (2019) conducted a study of cardiac arrest survivors and found that ICD recipients who received an ICD for secondary prevention recovered well after the implant unless they had a history of depression. A higher percentage of participants in this study were implanted for secondary prevention and had increased income, education, and physical activity, unlike Presciutti et al. (2019) reported high levels of psychosocial well-being. Higher socioeconomic stability enabled participants to access resources to assist in adjustment to living with their ICD, which may have contributed to their optimism and positive appraisals of having a second chance in life.

Mauro (2010) conducted a study on the impact of ICD shock reported the unpredictability and uncertainty of the shocks over time can cause accumulating fear of the device triggering, creating a disabling loss of control. Participants in Mauro's (2010) study also reported that individual's perceptions of safety and stability altered over time and were diminished due to ICD shocks. Investigators have identified that individuals living with an ICD experience ambiguity and vulnerability due to underlying heart disease and unpredictability of potential treatment via shocks (Dehghanadeh et al., 2018; Ooi, 2018; Pasyar et al., 2015). ICD shocks undermined participant's sense of control over their environment in this study, and this fear of the unknown decreased psychosocial well-being. Participants who received shocks more often also had multiple shocks, inappropriate shocks, higher number of procedures, and more complications. The combination of an ICD shock with other exacerbators may have influenced participants lower level of psychosocial well-being. Thylén et al. (2016) reported that in a large quantitative study of over 3000 participants, individuals had more ICD-related concerns than the shock itself. Investigators also reported that most ICD recipients who did not receive shocks did not report stressors or concerns with daily living (Flemme, Johansson et al., 2012). Similarly, in this study, participants who never received a shock reported less stress and higher acceptance of the device and viewed the ICD as a lifeline. Although circumstances with shocks may affect individuals, resilience and adaptation to living with an ICD improves their overall response when a shock does occur.

Participants who received shocks more often also had multiple shocks, inappropriate shocks, higher number of procedures, and more complications. The combination of an ICD shock with other exacerbators may have influenced participants lower level of psychosocial well-being. Thylén et al. (2016) reported that in a large quantitative study of over 3000 participants,

individuals had more ICD-related concerns than the shock itself. Although most of the participants in this study did not experience driving restrictions, those individuals who experienced multiple shocks, passed out, or were commercial drivers had long-term or permanent loss of driving privileges. Losing driving privileges affect daily living, limiting independent access to work, social networks, healthcare visits, and shopping. More extended periods of restriction may diminish personal feelings of control over their environment and loss of identity, mainly if the condition results in a job loss. Investigators also reported that most ICD recipients who did not receive shocks did not report stressors or concerns with daily living (Flemme, Johansson et al., 2012). Similarly, in this study, participants who never received a shock reported less stress, higher acceptance of the device, and viewed the ICD as a lifeline. Although circumstances with shocks may affect individuals, resilience and adaptation to living with an ICD improves their overall response when a shock does occur.

Stress Appraisal

Device-related distress was a predictor of individuals psychosocial well-being in this study, but body image was not. Participants who had higher levels of distress due to their ICD had lower levels of psychosocial well-being. In this study, individuals reporting device-related distress reported difficulty functioning after the ICD implant with feelings of depression and avoidance of past activities. Individuals living with an ICD who felt distressed were unable to return to previous roles and activities. Traumatic medical experiences that the individual cannot control and perceives as negative influences perceptions of well-being (Briere & Scott, 2015; Carlson & Dalenberg, 2000). Nationally, approximately 30% of ICD recipients experience anxiety and 20% depression related to ICD implant, and risk for pathological anxiety increased with the presence of shocks (Redhead et al, 2010). Low levels of depression or anxiety were

reported in this study, with a small percentage reporting pathological stress as they shared avoiding things they enjoy (15%) and finding it hard to function with the device (14%). In this study the presence of device related distress and signs of maladaptation to the ICD correlated with lower levels of psychosocial well-being. Amongst women, researchers reported an increased risk for anxiety from living with an ICD (Flemme, Johansson, et al., 2012; Wilson et al., 2013). Though not gender specific, Pedersen et al. (2013) found that individuals with weakened heart muscles or atrial fibrillation were at increased risk for anxiety (Pedersen et al., 2013).

Presciutti et al. (2019) conducted a qualitative study on the long-term perceptions of individuals living with an ICD. The investigators found that after cardiac arrest individuals reported depression, which significantly influenced their adjustment to an ICD overtime. The presence of depression, anxiety, and higher mortality burden decreased HRQoL for individuals living with an ICD in a study by Miller et al. (2019). Similarly, in this study, participants who experienced higher mortality after implant of the ICD for secondary prevention, experienced less feeling of control over their environment and more distress. Individuals in several studies who reported a history of anxiety, depression, or adverse psychological functioning before cardiovascular surgery had risk for concerns after surgery with mental health, lower personal growth or control (Hammash et al., 2019; Oxlad, 2008).

Ability to overcome hardships, disappointments, and manage circumstances related to living with an ICD impacts the individual's adjustment to the device. Participants in this study who experienced a sense of loss or stressful situations, such as restriction of driving or ICD shocks that impact daily life, reported higher levels of device related distress. Patients with a negative view of the ICD experience increased distress levels (McCaig et al., 2014). In this

study, younger participants living with an ICD due to a genetic condition had increased device-related distress. Although most participants in this study-reported a positive self-image, younger participants reported a more negative self-image. Larimer et al. (2016) conducted a qualitative study on the impact of younger recipients living with an ICD and found more body image concerns, fears about the future, and less support from others.

Acceptance

Participant's engagement in everyday activities significantly predicted higher levels of psychosocial well-being in this study; positive appraisal of the ICD did not. Participants in this study-reported resilience, a positive attitude toward living with an ICD, high levels of personal growth, and acceptance of their circumstances. Our findings are consistent with other studies which reported that individuals had a positive appraisal and acceptance of the ICD (Fumagalli et al., 2018; Haugaa et al., 2018; Wilson et al., 2013). Acceptance of the ICD was reported by participants not impacted daily by the device, versus the negative appraisal of participants experiencing a daily impact. Similarly, individuals in a study conducted by Ooi et al. (2016) who had a pessimistic outlook driven by fear, anxiety, ICD shocks, dependence, and loss of intimacy had less acceptance of the ICD. Investigators reported that individuals living with an ICD who experience fear and anxiety related to potential shocks, were ambivalent though they attempted to remain optimistic (Dehghanadeh et al., 2018; Ooi et al., 2018).

Flemme et al. (2011) conducted a study on ICD recipients and found individuals utilize self-strategies to process life changes and strengthen acceptance, including building daily routines, strengthening optimism through distraction, and hope for the future. A majority of participants in this study engaged in activities, which correlated with a sense of direction and meaning in life. Participants reengaged in life and demonstrated personal growth when they had

greater access to socioeconomic resources due to higher incomes, education, and social support. In this study, engagement within the community improved individual's living with an ICD acceptance and their ability to return to life. Participants may be attempting to normalize their life and seek out distractions from living with the ICD through engagement in activities of everyday living that occur when attending sports, neighborhood, or church groups. As in a study conducted by Flemme, Johansson et al. (2012), participants in this study with mastery over their environment reported acceptance of living with the ICD.

Social Facilitation

Social facilitation significantly predicted psychosocial well-being in this study. Multiple studies report negative buffering experiences with social support (Flurr et al., 2013; Hazelton et al.,2009; Tehee et al., 2017). In this study, maintaining positive relationships correlated with increased levels of psychosocial well-being. Participants who reported having trusting relationships with a specific person, family, or friends had higher levels of psychosocial well-being, with the most intimate and impactful support from a specific person in their lives. Though this study identified the significance of intimate partners, other researchers found that ICD recipients who expressed fear of hypervigilance from spouses over health status and an uncertain future isolated themselves from their families (Fluur et al., 2013; Humphreys et al., 2016). Engaging partners in care improves individual's adjustment to living with the ICD (Dougherty et al., 2019). Participants in this study identified family and friends as positive support for adjusting to life with an ICD; however, participants preferred sharing sensitive needs with their intimate partners. Other studies on individuals living with an ICD or chronic conditions report that altered family roles necessitates flexibility to meet the needs of the individual and the changing roles (Arestedt et al., 2014; Fluur et al., 2013; Hazelton et al.,-2009). The socioeconomic status of

participants in this study influenced the level of positive support they reported, with participants with higher status having improved psychosocial well-being. Participants with a higher socioeconomic status reported engagement in an increased variety of social networks. In contrast, participants with a lower status limited their engagement with neighborhood networks, possibly due to cost, transportation, or lack of access to resources. Participants with congestive heart failure reported higher levels of support, possibly due to the nature of the disease and varied levels of dependence and reliance on others as the disease progressed. In contrast, individuals who required more help with ADLs reported limited support from others. In a study on older adults living with chronic conditions, the presence of social support was associated with a reduction in the perception of events as traumatic (Tehee et al., 2017).

Implications of the Study

Uncertainty about living with an ICD and social facilitation influenced participant's psychosocial well-being in this study. Utilizing an ICD as a treatment modality has complex implications for the care of chronic cardiovascular conditions, including the risk of traumatic experiences and stress (Ford et al., 2016). Individuals living with an ICD may exhibit maladaptive responses when encountering stressful experiences (Briere & Scott, 2015). Promoting confidence for adults living with a chronic condition improves their ability to adapt to activities of daily living (CDC, 2017; Lindsay, 2010). A holistic approach to care ensures individuals living with an ICD receive ongoing clinical and psychosocial assessments and interventions to improve acceptance and adjustment (Williams et al., 2013). Exploring implications for research, healthcare, and policy for individuals living with an ICD will assist in optimizing their psychosocial well-being.

Implications for Research

Based on the findings from this study, future research is needed to further advance understanding of the impact of uncertainty and social facilitation on psychosocial well-being for individuals living with an ICD. The psychosocial concerns of individuals living with an ICD should be further explored with a focus on interventions to address maladaptive responses. Identifying and overcoming barriers to accessing ICD healthcare amongst diverse populations is needed. Additionally, conducting a qualitative study to further explore the barriers healthcare professionals' screening for psychosocial alterations in ICD recipients would provide insight into the development of strategies for effectively managing care. A follow-up intervention study measuring the efficacy of psychosocial screening tools and education would provide additional insight into effective ways to streamline access to interactive education. Identifying and testing models for integrated healthcare would be beneficial between cardiology specialty clinics, and behavioral health support, as those studies could identify the processes required to access specialized healthcare providers to meet patients' mental health needs. Specialized needs of individuals living with an ICD across the lifespan require varied support. At different ages concerns can vary and individuals living with an ICD may need support for managing child rearing, work continuation, physical activity, and end of life care. Studies on effective strategies for providing practical, supportive measures for individuals living with an ICD across their lifespan are needed.

Implications for Health Care and Education

Findings from this study reinforce the necessity to identify the psychosocial needs of individuals living with an ICD early on to support early adjustment. Early screening for psychological distress prior to the ICD implant provides an opportunity for early adjustment to

the device (Mauro, 2010). Developing an intradisciplinary screening tool is necessary to identify each individual's unique needs and provide them with quick referrals. Nurses, social workers, and psychologists should provide early screening and identification of patient's psychosocial needs for planning and implementing interventions, including education, stress management, and referrals (Dougherty et al., 2012). A majority of participants in this study reported a desire to explore how to adjust to living with an ICD from a psychosocial standpoint. Participants identified having limited access to resources from healthcare professionals to meet their needs. In-person and virtual support groups were utilized by participants to obtain the educational information and support they sought. Pedersen et al. (2018) conducted a study demonstrating the efficacy of personalized access to electronic educational tools for providing patient-centered support. Recommendations for developing interactive modules using artificial intelligence within electronic health records could enhance access to education and social support for individuals with an ICD. Interactive modules focused on the psychosocial well-being of individuals living with an ICD should include the reason for the ICD implant, navigating ICD shocks, returning to life after the ICD, reducing ICD-related distress, and building social networks. The access to mental health services to Individuals living with an ICD is influenced by the availability of qualified healthcare professionals and insurance. Making healthcare professionals readily accessible to individuals with an ICD could create additional training for the provision of cardiovascular psychosocial care, including screening, education, and support.

Implications for Policy

It is challenging to develop policies for individuals living with an ICD due to the complexity of their biopsychosocial domains of health. Individuals living with an ICD are vulnerable due to their morbidities, risk for mortality, potential for shocks, and the costs of care (NLM, 2006).

Access to care, social networks, economic stability, and social determinants of health (SDOH) impact individuals living with an ICD (Healthy People, 2019). Addressing the healthcare needs of individuals living with an ICD requires the incorporation of their SDOH to develop an ongoing plan of care. Information on individual SDOH assists health professionals to provide: (a) individualized care, (b) identification of needs, (c) personalized interventions, (d) access to resources, (e) access to social support networks, and (f) building of care teams (Healthy People, 2019). Policies on education and screening for underlying health concerns are essential to ensure that individuals living with an ICD receive adequate psychosocial resources. Therefore, policies directed at improving the psychosocial well-being of individuals living with an ICD should be structured, supportive, collaborative, and individualized to meet their needs (Flanagan et al., 2010; NLM, 2006). Polies for assisting individuals with an ICD to return to a productive life must include insurance coverage for exercise physiology care and screening for psychosocial needs and support.

Encouraging a Return to Life

Researchers found that individuals living with an ICD limit their activities and social outings due to uncertainty and fear of shocks (Berg et al., 2017; Flemme et al., 2011). Individuals may reduce activity and exercise after receiving the ICD due to fear of increasing their heart rates while reevaluating their activity limits. Early participation in structured exercise programs builds individuals with an ICD's trust in their bodies and technology (Berg et al., 2017). Coverage criteria for participation in monitored exercise programs within the United States does not include the implant of an ICD. The inclusion of ICD diagnosis coverage from Medicare, Medicaid, and private insurance within the monitored exercise program criteria is needed to promote active lifestyles, recovery, and adjustment after an ICD implant.

Expanding Technology

Remote device checks from home are a routine part of ICD follow-up. Individuals often complain about lack of communication regarding timely and accurate relaying of results to them (Lampert, 2013). As the remote monitoring system is outside of the standard electronic medical records platform, sharing information can be cumbersome. Innovation is needed to streamline the sharing of information to improve the efficiency of care delivery at limited cost.

Mental Health Support

Implementing a patient-centered health approach starts with providing a voice to individuals living with an ICD (Flanagan et al., 2010). The Centers for Medicare and Medicaid Services (CMS) (2017) mandate that individuals receive decision-making education prior to ICD implant to ensure patients are well informed prior to consenting to treatment with the device. Mental health screening, follow-up plans, and life transition coaching could be added though legislation to the existing mandatory education. Risk stratification screening for factors that impact psychosocial well-being prior to the ICD implant provides a baseline assessment to monitor for changes in psychosocial needs.

Targeted Care for Younger Participants

In this study, participants living with a threatening condition at a younger age identified more uncertainty with the ICD. Younger participants living with an ICD face unique challenges affecting their work, insurance coverage, financial stability, and family life that may affect their psychosocial well-being. Therefore, health professionals should incorporate supportive measures into care plans to assist in life challenges at various stages of life.

Limitations

Policies enacted during the COVID-19 pandemic made recruitment from traditional sources such as health systems and doctors' offices difficult. Recruitment for this study relied heavily on strategies including flyers, consent to communicate, and snowball sampling, which may have limited access to diverse populations. Despite efforts to enroll a diverse population of participants, there was limited diversity amongst the participants limiting the dissemination of the findings broadly to the larger population. Self-report cross sectional measures assessed individual perceptions at a moment in time and some participants may give alternate responses at varying stages of adjustment to the ICD.

Chapter Summary

The study findings support the hypothesis that uncertainty living with an ICD and social facilitation predict psychosocial well-being. Participants overall accept the device as a lifeline and necessary treatment, but those who experienced a challenging event need additional support to adjust to living with an ICD. Individual stories revealed that concerns with anxiety vary over time and with changing circumstances. Therefore, those living with an ICD should be assessed frequently for adjustment to their changing needs and reactions to life-altering events such as ICD shocks, terminal illness, job loss, or changes in supportive networks.

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Appendix A: Consents for Use of Measurement Instruments

Psychological Well-being Scale (PWB):

From: THERESA M BERRIE **berrie@wisc.edu**
Tue 10/6/2020 9:44 AM
To: Mary Margaret McMahon Bullis

1- Ryff PWB Scales.docx 92 KB; 2- Ryff PWB Reference Lists.docx 151 KB; 2 attachments (243 KB)

Greetings,

Thanks for your interest in the well-being scales.
I am responding to your request on behalf of Carol Ryff.
She has asked me to send you the following:

You have her permission to use the scales for research or other non-commercial purposes.

They are attached in the following files:

"Ryff PWB Scales" includes:
- psychometric properties
- scoring instructions
- how to use different lengths of the scales
  (see note about the 18-item scale, which is not recommended)

"Ryff PWB Reference Lists" includes:
- a list of the main publications about the scales
- a list of published studies using the scales

There is no charge to use the scales and no need to send us the results of your study.
We do ask that you please send us copies
of any journal articles you may publish using the scales to:
berrie@wisc.edu and cryff@wisc.edu.

Best wishes for your research,

Theresa Berrie
UW-Madison Institute on Aging
berrie@wisc.edu
Hours: Tues-Thurs, 7am-3:30pm

From: Mary Margaret McMahon Bullis [**mailto:mcmaho64@uwm.edu**]
Sent: Friday, October 02, 2020 4:06 PM
To: CAROL RYFF <**cryff@wisc.edu**>
Subject: Permission to use PWB scale in my dissertation

Dr Ryff

My name is Mary Bullis and I am a PhD student in the online cohort at the University of Wisconsin- Milwaukee. I am in the dissertation stage of my program. I have enjoyed reading your research on psychosocial well-being as part of the literature reviews I conducted. I am studying T*he Psychosocial Well-Being of Adults Living with an Implantable Cardioverter Defibrillator (ICD).* I chose this topic after exploration during my coursework on chronic cardiovascular conditions and engagement in self-management. My interest in studying individuals with an ICD stems from my time working as an Electrophysiology nurse clinician. I will be utilizing the Theories of Uncertainty of Illness and Theory of Self-management to explore factors of uncertainty with living with an ICD that correlate with overall psychosocial well-being.

I am writing to request your permission to utilize the Psychological Wellbeing Scale (PWB) in my work. My major professor is Dr Julia Snethen. Let me know if you have any questions. Thank you for your time.

Best Regards,
Mary

Florida Patient Acceptance Scale (FPAS):

Sears, Samuel <SEARSS@ecu.edu>
Sun 10/4/2020 12:09 PM
To: Mary Margaret McMahon Bullis

ICD BIBLIOGRAPHY 2020.doc165 KB; sears-tripp fsas sept 2019.pdf 176 KB; FPAS scoring for clinic.doc 146 KB; ASSESS_FPAS.doc 36 KB; FSAS.pdf 257 KB; living heart am psychologist 2018.pdf 319 KB; sears ford ehj editoriral 2019.pdf290 KB; Show all 7 attachments

Mary,

Thank you for your kind note. I am pleased to provide you with approval to use the FPAS and FSAS free of charge as you see fit. I have attached some papers and the measures and scoring. I have also attached some listings of upcoming papers of interest. I would be happy to help in any way with your research. I love this work and I think that ICD patients benefit from our collective efforts. Thanks

Sam

Samuel F. Sears, Ph.D.
Professor and Licensed Psychologist
East Carolina University
Department of Psychology
Department of Cardiovascular Sciences
252 328-6118

From: Mary Margaret McMahon Bullis <mcmaho64@uwm.edu>
Sent: Friday, October 2, 2020 4:35 PM
To: Sears, Samuel <SEARSS@ecu.edu>
Subject: Permission to use FPAS in my PhD dissertation

Dr Sears

My name is Mary Bullis and I am a PhD student in the online cohort at the University of Wisconsin- Milwaukee. I am in the dissertation stage of my program. I have enjoyed reading your research on adults with an ICD as part of the literature reviews I conducted. I am studying T*he Psychosocial Well-Being of Adults Living with an ICD.* I chose this topic after exploration during my coursework on chronic cardiovascular conditions and engagement in self-management. My interest in studying individuals with an ICD stems from my time working as an Electrophysiology nurse clinician. I will be utilizing the Theories of Uncertainty of Illness and Theory of Self-management to explore factors of uncertainty with living with an ICD that correlate with overall psycho-social well-being.

I am writing to request your permission to utilize the Florida Patient Acceptance Survey (FPAS) in my work. Let me know if I should reach out to any of your colleagues for permission, such as Dr Jason Burns. My major professor is Dr Julia Snethen. Let me know if you have any questions. Thank you for your time.

Best Regards,
Mary

Multidimensional Scale of Perceived Social Support (MSPSS):

Zimet, Gregory D <gzimet@iu.edu>
Fri 10/23/2020 3:33 PM
To: Mary Margaret McMahon Bullis

0732 Zimet - MSPSS - Chapter 1998.pdf 539 KB; MSPSS References.pdf 128 KB; MSPSS.pdf 20 KB; 3 attachments (688 KB)

Dear Mary,

You have my permission to use the Multidimensional Scale of Perceived Social Support (MSPSS) in your research. I have attached a copy of the scale (with scoring information on the 2nd page), a document listing several of the articles that have reported on the reliability and validity of the MSPSS, and a chapter that I wrote about the scale.

I hope your research goes well.

Best regards,

Greg Zimet

Gregory D. Zimet, PhD, FSAHM
Professor of Pediatrics & Clinical Psychology
Co-Director, IUPUI Center for HPV Research
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gzimet@iu.edu

From: Mary Margaret McMahon Bullis
Mon 10/19/2020 1:35 AM
To: gzimet@iu.edu
To: Gregory D. Zimet, PhD
Indiana University School of Medicine

Dr Zimet,
My name is Mary Bullis and I am a PhD student in the online cohort at the University of Wisconsin- Milwaukee. I am in the dissertation stage of my program. I am studying T*he Psychosocial Well-Being of Adults Living with an ICD.* I chose this topic after exploration during my coursework on chronic cardiovascular conditions and engagement in self-management. My interest in studying individuals with an ICD stems from my time working as an Electrophysiology nurse clinician. I will be utilizing the Theories of Uncertainty of Illness and Theory of Self-management to explore factors of uncertainty with living with an ICD that correlate with overall psycho-social well-being.

I am writing to request your permission to utilize the Multidimensional Scale of Perceived Social Support (MSPSS) in my work. My major professor is Dr Julia Snethen. Let me know if you have any questions. Thank you for your time.

Best Regards,
Mary

Appendix B: Patient Characteristics Questionnaire

Patient Characteristics Questionnaire

*Please **circle the letter** next to each category item or fill in the blank that best describes you.*

General Questions:

1. What is your gender? a) Man b) Woman
   c) Another gender identity not listed here (please specify _____)
2. Current age: _____
3. Height /Weight: ____ft___ inches / _____lbs/kg
4. Marital Status: **a)** Single **b)** Married **c)** Widowed **d)** Divorced **e)** Domestic Partner
5. What is your Race/Ethnicity**?**
   a) Caucasian / White **b)** African American / Black **c)** Asian / Pacific Islander
   d) Hispanic / Latino / Latin American **e)** Middle Eastern **f)** Other _____
6. Do you Identify with any Religion?
   a) Christian **b)** Protestant **c)** Catholic **d)** Jewish **e)** Islam **f)** Other _____ **e)** None
7. What level of Education or Degree did you obtain?
   a) <12 years **b)** High School / GED **c)** Associate **d)** Bachelors **e)** Masters or higher
8. What is your **annual** family income?
   a) <30,000 **b)** 30,000- 50,000 **c)** 50,000-100,000 **d)** over 100,000
9. Do you have any of the following conditions? (circle all that apply)
   a) Diabetes **b)** Genetic condition **c)** Weakened heart muscle **d)** Atrial Fibrillation
   e) Congestive heart failure **f)** High blood pressure **g)** Mental health condition
10. What is your smoking history?
    a) Half pack daily **b)** One pack Daily **c)** More than one pack daily **d)** Former Smoke
    e) Never Smoker **f)** Chewing tobacco **g)** Other _____
11. Do you attend any gatherings or activities with the following groups? (circle all that apply)
    a) Neighborhood **b)** Church **c)** Work **d)** Sports **f)** Political **e)** Support
12. How much help do you need in doing your activities of daily living?
    a) I am living independently **b)** some help with laundry and cooking
    c) weekly help with a bath and shopping **d)** I am dependent on others completely

Device Related Questions:

13. How many device procedures have you had?

a) One **b)** Two **c)** Three **d)** Four **e)** Five or more

14. Did you have any of the following complications from your procedure(s)?

a) Dislodged lead **b)** Broken lead **c)** Recall of device or lead **d)** Infection

e) Inappropriate shock(s) **f)** I don't know

15. What was the reason your device was implanted?

a) To prevent sudden death, but I have no history of arrythmia or cardiac arrest

b) I had a cardiac arrest or life-threatening rhythm **c)** I don't know why

d) Other _____

16. How many times did you receive a shock from your device?

a) Never **b)** One time **c)** Two separate times **d)** Three or more separate times

e) multiple shocks within one day

17. Has your driving been restricted or revoked since getting your device?

a) Never **b)** After implant for short period of time **c)** For 3 months **d)** For 6 months

e) I don't drive at all now **f)** I lost driving privileges as a Truck or School Bus driver

18. Have you had a job change or job loss since getting your device?

a) No, I work full time **b)** No, I work part time **c)** Yes, I changed to part time

d) Yes, because I got the device **e)** Yes, but not because of the device **f)** Yes, I retired

19. How often do you walk, exercise, or engage in physical activity during the week?

a) None **b)** once or twice a week **c)** every other day **d)** every day

If you engage in activity during the week, how intense would you describe your activity level?

a) Mild activity level (leisurely walk)

b) moderate activity level (mild aerobics, walk/run)

c) Moderate to Intense activity level (1 to 2 hour workouts, run/walk)

d) Intense activity level (intense workouts with trainer, weightlifting, marathons)

Appendix C: Florida Patient Acceptance Scale (FPAS)

FPAS

We want to understand what it is like for you to live with a medical device. Below are some statements that describe living with a medical device. Please rate the extent to which you agree or disagree with each of the following statements by checking the most appropriate box.

	Strongly Disagree	Mostly Disagree	Neither Agree or Disagree	Mostly Agree	Strongly Agree
1. Thinking about the device makes me depressed.	1	2	3	4	5
2. When I think about the device I avoid doing things I enjoy.	1	2	3	4	5
3. I avoid my usual activities because I feel disfigured by my device.	1	2	3	4	5
4. It is hard for me to function without thinking about my device.	1	2	3	4	5
5. My device was my best treatment option.	1	2	3	4	5
6. I am confident about my ability to return to work if I want to.	1	2	3	4	5
7. I am safer from harm because of my device.	1	2	3	4	5
8. The positive benefits of this device out-weigh the negatives.	1	2	3	4	5
9. I have continued my normal sex life.	1	2	3	4	5
10. I would receive this device again.	1	2	3	4	5
11. I know enough about my device.	1	2	3	4	5
12. I am careful when hugging or kissing my loved ones.	1	2	3	4	5
13. I have returned to a full life.	1	2	3	4	5
14. I feel that others see me as disfigured by my device.	1	2	3	4	5
15. I feel less attractive because of my device.	1	2	3	4	5
16. I am knowledgeable about how the device works and what it does for me.	1	2	3	4	5
17. I am not able to do things for my family the way I used to.	1	2	3	4	5
18. I am concerned about resuming my daily physical activities.	1	2	3	4	5

Appendix D: Multidimensional Scale of Perceived Social Support (MSPSS)

Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
Circle the "2" if you **Strongly Disagree**
Circle the "3" if you **Mildly Disagree**
Circle the "4" if you are **Neutral**
Circle the "5" if you **Mildly Agree**
Circle the "6" if you **Strongly Agree**
Circle the "7" if you **Very Strongly Agree**

		Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2.	There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3.	My family really tries to help me.	1	2	3	4	5	6	7
4.	I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6.	My friends really try to help me.	1	2	3	4	5	6	7
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7

Appendix E: Ryff's Scales of Psychological Well-Being (PWB)

Ryff's Scales of Psychological Well-Being (PWB) • 42 Item Version Formatted

The following set of questions deals with how you feel about yourself and your life. Please remember that there are no right or wrong answers.

Circle the number that best describes your present agreement or disagreement with each statement.	StronglyDisagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
1. I am not afraid to voice my opinions, even when they are in opposition to the opinions of most people.	1	2	4	4	5	6
2. In general, I feel I am in charge of the situation in which I live.	1	2	3	4	5	6
3. I am not interested in activities that will expand my horizons.	1	2	3	4	5	6
4. Most people see me as loving and affectionate.	1	2	3	4	5	6
5. I live life one day at a time and don't really think about the future.	1	2	3	4	5	6
6. When I look at the story of my life, I am pleased with how things have turned out.	1	2	3	4	5	6
7. My decisions are not usually influenced by what everyone else is doing.	1	2	3	4	5	6
8. The demands of everyday life often get me down.	1	2	3	4	5	6
9. I think it is important to have new experiences that challenge how you think about yourself and the world.	1	2	3	4	5	6
10. Maintaining close relationships has been difficult and frustrating for me.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	StronglyDisagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
11. I have a sense of direction and purpose in life.	1	2	3	4	5	6
12. In general, I feel confident and positive about myself.	1	2	3	4	5	6
13. I tend to worry about what other people think of me.	1	2	3	4	5	6
14. I do not fit very well with the people and the community around me.	1	2	3	4	5	6
15. When I think about it, I haven't really improved much as a person over the years.	1	2	3	4	5	6
16. I often feel lonely because I have few close friends with whom to share my concerns.	1	2	3	4	5	6
17. My daily activities often seem trivial and unimportant to me.	1	2	3	4	5	6
18. I feel like many of the people I know have gotten more out of life than I have.	1	2	3	4	5	6
19. I tend to be influenced by people with strong opinions.	1	2	3	4	5	6
20. I am quite good at managing the many responsibilities of my daily life.	1	2	3	4	5	6
21. I have a sense that I have developed a lot as a person over time.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	StronglyDisagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
22. I enjoy personal and mutual conversations with family members or friends.	1	2	3	4	5	6
23. I don't have a good sense of what it is I'm trying to accomplish in life.	1	2	3	4	5	6
24. I like most aspects of my personality.	1	2	3	4	5	6
25. I have confidence in my opinions, even if they are contrary to the general consensus.	1	2	3	4	5	6
26. I often feel overwhelmed by my responsibilities.	1	2	3	4	5	6
27. I do not enjoy being in new situations that require me to change my old familiar ways of doing things.	1	2	3	4	5	6
28. People would describe me as a giving person, willing to share my time with others.	1	2	3	4	5	6
29. I enjoy making plans for the future and working to make them a reality.	1	2	3	4	5	6
30. In many ways, I feel disappointed about my achievements in life.	1	2	3	4	5	6
31. It's difficult for me to voice my own opinions on controversial matters.	1	2	3	4	5	6
32. I have difficulty arranging my life in a way that is satisfying to me.	1	2	3	4	5	6

Circle the number that best describes your present agreement or disagreement with each statement.	StronglyDisagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
33. For me, life has been a continuous process of learning, changing, and growth.	1	2	3	4	5	6
34. I have not experienced many warm and trusting relationships with others.	1	2	3	4	5	6
35. Some people wander aimlessly through life, but I am not one of them.	1	2	3	4	5	6
36. My attitude about myself is probably not as positive as most people feel about themselves.	1	2	3	4	5	6
37. I judge myself by what I think is important, not by the values of what others think is important.	1	2	3	4	5	6
38. I have been able to build a home and a lifestyle for myself that is much to my liking.	1	2	3	4	5	6
39. I gave up trying to make big improvements or changes in my life a long time ago.	1	2	3	4	5	6
40. I know that I can trust my friends, and they know they can trust me.	1	2	3	4	5	6
41. I sometimes feel as if I've done all there is to do in life.	1	2	3	4	5	6
42. When I compare myself to friends and acquaintances, it makes me feel good about who I am.	1	2	3	4	5	6

Appendix F: Consent Form

University of Wisconsin-Milwaukee
Informed Consent to Participate in Research

Study title: Living with an Implantable Cardioverter Defibrillator - Impact of Perceptions on Psychosocial Well-Being

Researcher[s]:
Mary McMahon Bullis, MAN, RN, CCRN-K / PhD Student Principal Investigator
University of Wisconsin- Milwaukee, College of Nursing

Julia Snethen, PhD, RN, FAAN / Principal Investigator
University of Wisconsin- Milwaukee, College of Nursing

UWM Research Team:
Julie Ellis, PhD, RN, GCNS-BC
Colleen Galambos, PhD, LCSW, LCSW-C, ACSW, FGSA
Murad Taani, PhD, MPH, RN
Vipavee Thongpriwan, PhD, RN, CNE

We are inviting you to answer some questions for a research project. We want to find out how you are feeling about living with an implantable cardioverter defibrillator (ICD). The questions that we will ask you on the survey will include questions about your heart condition, your stress level, and how well you are managing to live with an implantable cardioverter defibrillator (ICD). The survey includes questions about the support you receive from your spouse or significant other, family, or friends. We will also ask you about how well you feel you are adjusting to life with your device including your activity, friendships, home life, and general life. At the end of the survey, you will be asked an additional question: "What information about your experience living with an ICD has not been covered in this survey, that would be helpful for me to know?"

Participation in this survey is voluntary. No names will be on this data, so no one will know what answers you gave for each of the questions, except the nurse who is asking the questions. We will put a number on each of the surveys, so that we can analyze the data, but no names will be on the surveys. It is no problem if you don't want to answer the questions. If you start to answer the questions, you can change your mind and stop answering the questions at any time while the nurse is asking you questions. If you wish to respond to the final question, your response will be audio recorded to ensure that the researcher accurately records your thoughts. After your response is written down from the recording as data, the recording will be deleted. Once you have completed answering the questions on the survey and the final question, and the nurse enters the data onto the computer, and submits it, we will be unable to identify you with an any of the data. No names will be attached to the data, meaning there will be now no way to know which data is yours. At that point, it will not be possible to remove your anonymous (unidentified) data from the computer.

Estimated number of participants: We anticipate enrolling up to 200 individuals in this study.

Possible Risks:

- Some questions you may feel uncomfortable answering. You can skip questions or stop answering a question at any time up during the survey. Mental health resources and assistance are available as needed (see bottom of consent form). Once you have completed answering the questions on the survey, and the nurse enters the data onto the computer, and submits it, we will be unable to identify you with an any of the data.
- Data security: We are using a secure computer system; however, anytime you share information online there are risks. Those risks cannot be completely eliminated.
- Breach of confidentiality: There is a little chance that anyone would be able to get your anonymous data from the computer, and as your name is not on the data, they would not know which answers were your answers. We are limiting this risk in the following ways:
  - Data is anonymous: meaning, we will not have your name or any identifying information that would tell people who we collected the data from. We will put a number on each survey, just so we can analyze the data.
  - We will store all electronic data on a password-protected, encrypted computer.
  - We will not put any data in the computer that tells us who you are, like your phone number, e-mail or address. We will destroy any copies of your phone number, email, or address after you finish answering the questions for the survey.
  - We will not access or get any information from your electronic health record.
- The risks from this study to your physical, emotional, social, professional, or financial well-being are considered to be 'less than minimal'.

Possible benefits: You will not have any direct benefit from this study. Others who have an implantable cardioverter defibrillator (ICD) and the health professionals caring for them may benefit from your helping us learn more about living with the device. Having information about how individuals live with the ICD device may improve the way we care for our patients.

How long will it take? About 30-60 minutes, depending on how much you would like to share with us. Some participants may take longer if they need time to reflect on questions.

Costs: There is no cost to you for answering the questions we put on the survey other than your time.

Compensation: A gift card of $25 will be offered to participants after completing the survey as a token of appreciation for their time. The gift card will be sent via text to participant mobile device at the end of the study. Participants may decline the gift card. Phone numbers will be deleted once the gift card is sent. Since this is an anonymous study, those who received a gift card will be logged by number only.

Estimated number of participants: We plan to have up to 200 people answer questions for this study.

Future research: We may share anonymous data (data that does not include your name or identifying information) with other researchers or for use in future additional research with this data. We would not give you specific details about these future research studies.

Funding source: Sigma Chi at Large Chapter, Bethel University, St Paul, MN.

Where will data be stored? Data will be stored on the researchers' password protected computer and on the servers for the online survey software (Qualtrics).

How long will data be kept? The data will be retained for analysis and use in papers to share what we learn with other nurses and healthcare providers within the research community. We may share anonymous data (data that does not include your name or identifying information) with other researchers or for use in future additional research using this data.

Who can see my data?

- We (the researchers) will have access to unidentified data with no names, birthdate, address, etc. We will identify the data by number only so we can analyze the data and complete the study.
- Agencies that enforce legal and ethical guidelines, such as
  - The Institutional Review Board (IRB) at UWM
  - The Office for Human Research Protections (OHRP)
- We may share our findings in publications or presentations. If we do, the data and results will be aggregated (combined with other persons answers), and no individual responses will be presented.

Consent document: The consent will be on the first page of the survey. We will review the consent with you in detail prior to asking you any questions. We will obtain your verbal consent to complete the survey in place of your signature. By answering the questions that the nurse asks, you are agreeing that you are 18 years of age or older, and agreeing to participate in this study.

Questions about the research, complaints, or problems: Contact Mary McMahon Bullis, phone: (715) 255-0847 or email: mcmaho64@uwm.edu

Questions about your rights as a research participant, complaints, or problems: Contact the UWM IRB (Institutional Review Board) at 414-662-3544 / irbinfo@uwm.edu.

Mental Health Free Hotlines:
The National Alliance on Mental Illness (NAMI): 1-800-950- 6264, info@nami.org. Monday–Friday from 10 a.m. to 6 p.m. EST.
SAMHSA National Helpline: 1-800-662-HELP (4357) Available 24/7/365
Minnesota: Minneapolis Hennepin County Medical Center 1-612-873-2222
Wisconsin: The Crisis Center of Family Services 1-920-436-8888
Crisis Text Line: Text CONNECT to 741741. 24 hours
IRB #: 21.318
IRB Approval Date: 5/21/2021

Appendix G: Recruitment Flyer

Are you Living with an Implantable Cardioverter Defibrillator?

If you are 18 or older and have an Implantable Cardioverter Defibrillator (ICD), you may be eligible to participate in this research study

Help us improve the Well-being of those Living with an Implantable Cardioverter Defibrillator (ICD)

We are gathering information to find out how we can help individuals to live well and have a good sense of well-being.

- We would like to explore your feelings regarding your ICD
- How the ICD affects your life
- We would also like to find out about your relationship with your significant others, family or friends

Location

- Share your thoughts with a nurse researcher
- Nurse researcher will record your answers by phone or virtually
- One-time participation required

Are you eligible?

- ICD implanted over 3 months ago
- 18 years of age or older
- English is primary or secondary language

$25 Gift Card available upon completion of survey

To participate or to see if you can participate, call or email the nurse researcher:
Mary McMahon Bullis

mcmaho64@uwm.edu
(715) 255-0874

UWM UNIVERSITY of WISCONSIN MILWAUKEE

PhD Student Researcher: Mary McMahon Bullis, MAN, RN, CCRN-K
Phone: (715) 255-0874 Email: mcmaho64@uwm.edu Study IRB # 21.318
Under the direction of Julia Snethen, PhD, RN, FAAN, UWM-College of Nursing

Approved for use by UWM IRB
Effective 7/6/2022
IRB Study Number: 21.318

Appendix H: Permission to Contact Forms

Permission to Contact Form (General)

The following person gave verbal permission to _____ for Mary McMahon Bullis MA, RN, CCRN-K or staff from the "**Defibrillator Study**"* to contact them regarding participation in this study. They understand confirmation of permission to contact will be verified and they will be given more information on this study during this contact with study staff. After obtaining more information they may or may not choose to participate in the study. This contact information will be destroyed after contact and/or survey completed.

Date: _____

First Name Only: _____

Telephone Number (include area code): _____

Best time to call (AM, afternoon, PM): _____

*Full study name: **Living with an Implantable Cardioverter Defibrillator - Impact of Perceptions on Psychosocial Well-Being**

Permission to Contact Form - M Health Fairview

The following persons have given verbal permission to M Health Fairview providers or staff for Mary McMahon Bullis MA, RN, CCRN-K, the researcher on the "**Living with ICD Study,**"* to contact individuals who might be interested in taking part in this study. The individuals who provided permission for Ms. McMahon Bullis to contact them will receive a phone call, and at that time, will be given specific details about this study. After obtaining more information the individuals may or may not choose to be in the study. This contact information below will be shredded or deleted after phone contact and/or survey completed.

	Date	First Name Only	Telephone Number (with area code)	Best time to call
1				AM Afternoon PM
2				AM Afternoon PM
3				AM Afternoon PM
4				AM Afternoon PM
5				AM Afternoon PM
6				AM Afternoon PM
7				AM Afternoon PM
8				AM Afternoon PM
9				AM Afternoon PM
10				AM Afternoon PM

*Full study name: **Living with an Implantable Cardioverter Defibrillator - Impact of Perceptions on Psychosocial Well-Being**

Approved for use by UMN IRB
Effective on 3/4/2022
IRB Study Number: STUDY00014109

Appendix I: Data Analysis Plan

Data Analysis Plan

Research Questions	**Variables**	**Statistics**
1. What is the knowledge level of an ICD and conditions among adult participants with an ICD?	IV - Knowledge and Patient Characteristics □FPAS Knowledge (2 Items) □Severity of conditions: Comorbidities Implant Criteria ICD Shocks	Descriptive analysis Pearson's Correlation coefficient statistical analysis
2. What is the individual stress appraisal among adult participants with an ICD?	IV- Stress Appraisal □FPAS Device-Related Distress (5 Items) □FPAS Body Image (2 Items)	Descriptive analysis Pearson's Correlation coefficient statistical analysis
3. What is the acceptance level of an ICD among adult participants with an ICD?	IV – Acceptance □Return to Life (4 Items) □Positive Appraisal (4 Items) □Return to Sex Life (1 Item)	Descriptive analysis Pearson's Correlation coefficient statistical analysis
4. What is the level of social facilitation among adult participants with an ICD?	IV- Social Facilitation □MSPSS Total Score (12 Items) □MSPSS Subscales (4 Items) Special Person Family Friends	Descriptive analysis Pearson's Correlation coefficient statistical analysis
5. What is the level of psychosocial well-being among adult participants with an ICD?	IV – Psychosocial Well-Being □PWB Total Score (42 Items) □PWB Subscales (7 Items) Autonomy Environmental Mastery Personal Growth Positive Relations Purpose in Life Self-Acceptance	Descriptive analysis Pearson's Correlation coefficient statistical analysis
6. Examine the association between health condition, individual stress appraisal, acceptance of ICD, and social	DV – Psychosocial Well-Being □ PWB Total Score (42 Items) for all models	Descriptive analysis

facilitation with psychosocial well-being among adult participants with an ICD.	Age and Gender for all Models Model One IV- Knowledge and Patient characteristics - FPAS Knowledge (2 Items) - Severity of conditions: Comorbidities Implant Criteria ICD Shocks Model Two IV- Stress Appraisal - FPAS Device-Related Distress (5 Items) - FPAS Body Image (2 Items) Model Three IV – Acceptance Return to Life (4 Items) Positive Appraisal (4 Items) Return to Sex Life (1 Item) Model Four IV - Uncertainty (combination of stress appraisal and acceptance) FPAS Total Score Severity of conditions: Comorbidities Implant Criteria ICD Shocks Model Five IV- Social Facilitation MSPSS Total Score (12 Items)	Pearson's Correlation coefficient statistical analysis Simultaneous Multiple Regression

CURRICULUM VITAE

Mary McMahon Bullis, PhD, MAN, BSN, BS, RN, CCRN-K, PHN

Education

Doctor of Philosophy Degree, Nursing (PhD), *University of Wisconsin-Milwaukee*, Wisconsin, 2023

Masters Arts, Nursing (MA), *Bethel University*, St Paul, Minnesota, 2013

Bachelor of Science, Nursing (BSN), *Bethel University*, St Paul, Minnesota, 2013, Nursing Honors

Bachelor of Science, Liberal Studies (BS), *Excelsior College*, Albany, New York, 1994

Associate of Science, Nursing (ASN), *Southern University*, Collegedale, Tennessee, 1991, Nursing Honors

Military:

United States Navy, *Interior Communications Electrician (IC-2):* Petty Officer 2nd Class (E-5), 1983-87

Dissertation Title: Living with an Implantable Cardioverter Defibrillator: Impact of Perceptions on Psychosocial Well-Being

Publications:

Ulmen, B., Rommelfaenger, M., **McMahon Bullis, M.,** & Weis, K. (in press) *Recognizing the Unsung Heros: Bridging Lifelong Learning to the Bedside*. Nurse Educator.

Mikell, M., Snethen, J. A., Gonzalez, C., Treisman, P., **McMahon-Bullis, M.,** & Suero, R. (2023). *Health and Wellness CBPR Program for Latino Youth in a Faith-based Community* [Manuscript submitted for publication]. Journal of Christian Nursing.

Graf, M., **McMahon Bullis, M.** Anderson, A., Snethen, J., Silvestre, E., & Mkandawire-Valhmu,L. (2023). *A Qualitative Analysis of Latina Migrant Farmworkers' Perception of Mental Health: Voices from the Upper Midwest.* [Manuscript submitted for publication]. The Journal of Transcultural Nursing

McMahon Bullis, M. M., Snethen, J. A., Ellis, J., Taani, M. H., Galambos, C., & Thongpriwan, V. (2022). *Uncertainty in Living with an Implantable Cardioverter Defibrillator: A Concept Analysis of Social Facilitation.* [Manuscript in preparation]. College of Nursing, University of Wisconsin-Milwaukee.

Treisman, P., Kent, D., Sima, C., **McMahon Bullis, M.,** Parizek, R., & Snethen, J. (in press). *Writingcamp: Supporting Dissertator Writing and Self-Care During the COVID-19 Pandemic*. Imprint.

McMahon Bullis, M. M., Snethen, J. A., Ellis, J., Galambos, C., Taani, M. H., & Thongpriwan, V. (2021). *Identifying Factors Influencing Living with an Implantable Cardioverter Defibrillator from a Trauma Informed Lens: A Systematic Review*. [Manuscript in preparation]. College of Nursing, University of Wisconsin-Milwaukee.

McMahon Bullis, M. & Gonzalez, C. M. (2021). *Building a Gerontology Student Portfolio: Nurse Educator Resource* [iBook].

McMahon Bullis, M. (2013). *Assisting the Bereaved After a Sudden or Traumatic Death*. Bethel University, St Paul, MN.