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Social Determinants of Health and Disparities in Outcomes Related to Cardiovascular Health in Vulnerable Populations

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SOCIAL DETERMINANTS OF HEALTH AND DISPARITIES IN OUTCOMES
RELATED TO CARDIOVASCULAR HEALTH IN VULNERABLE POPULATIONS

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Dissertation

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A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Nursing at the University of Kentucky

By

Jennifer Miller PhD candidate, MSN, RN

Lexington, Kentucky

Director: Debra K. Moser, Professor and Linda C. Gill Chair in Cardiovascular Nursing

Lexington, Kentucky

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Abstract

The purpose of this dissertation was to explore the mechanism of association between social determinants of health (SDH), particularly limited health literacy, and disparate outcomes related to cardiovascular disease in vulnerable populations. Specific aims were to 1) compare quality of life (QOL), anxiety, and depressive symptoms between genders in implantable cardioverter defibrillator (ICD) recipients; 2) examine the association between multi-morbidity burden and QOL; 3) determine whether health literacy levels independently predict CVD risk in the male prison population; 4) examine the relationship between health literacy and decisiveness regarding end of life (EOL) choices, and 5) examine SDH as predictors of perceived poor health status in ICD recipients. Specific aim one was addressed by analysis of data collected from individuals in the Swedish ICD and Pacemaker Registry. Multiple linear regression was used to determine predictors of anxiety, depression, and quality of life in men and women. A higher prevalence of anxiety symptoms in women was noted with no differences in depressive symptoms noted between the genders. The majority of the variance in the predictive models for QOL was explained by the addition of the psychosocial variables for both genders. Specific aim two was addressed by analysis of data collected from individuals in the Swedish ICD and Pacemaker Registry. Logistic regression was used to determine predictors of QOL. Greater multi-morbidity burden was associated with lower QOL in ICD recipients. Specific aim three was addressed by analysis of data collected from male inmates enrolled in a bio-behavioral educational and counselling intervention program to reduce CVD risk. Nonlinear regression was used to determine whether health literacy was an independent predictor of CVD risk while controlling for social and clinical

variables. Inmates with adequate levels of health literacy had lower ten year CVD risk profiles than those inmates with inadequate health literacy. Specific aim four was addressed by analysis of data collected from ICD recipients. Multinomial regression was used to determine predictors of decisiveness regarding EOL choices. Within the context of terminal illness, health literacy and race were found to be predictors of decisiveness regrading generator replacement while gender was found to be a predictor of decisiveness regarding the withdrawal of defibrillation therapy. Specific aim five was addressed by analysis of data collected from ICD recipients. Logistic regression was used to determine predictors of perceived poor health status. Residential status in the Central Appalachian region of Kentucky, not working outside the home, higher levels of health literacy, and comorbid depression were predictors of perceived poor/very poor health status.

KEYWORDS: cardiovascular disease; vulnerable populations; social determinants of health; health literacy

Jennifer Miller

February 14, 2017

SOCIAL DETERMINANTS OF HEALTH AND DISPARITIES IN OUTCOMES
RELATED TO CARDIOVASCULAR HEALTH IN VULNERABLE POPULATIONS

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<u>February 14, 2017</u>
Date

Dedication

For my children, my family, and my love, Jeff. Everything I do, I do for you.

In Memory

Ethel Jones White

Mary Lee Montgomery

Joseph Michael Glardon

Acknowledgments

I have so many people to thank for their support and encouragement over the years. Without the underpinning of their love, strength, and hope I would not be here today.

In my life I have been surrounded by strong women. My mother Lynda, my grandmother Ethel, and my aunts Barbara, Carolyn, and Mary Lee paved the way by showing me how to handle adversity and success with grace, humility, and compassion. This has been of particular importance in my life as a mother, a nurse, and an educator. I could never have achieved my goals without the support of my family, those related by blood and by love.

I was lucky enough to have the love of two fathers. My biological father Joseph Michael Glardon and my adopted father Ronald Carpenter. Through them I learned the meaning of sacrifice and unconditional love. My brothers Michael Lee, James, and Joseph have been my confidants and my support throughout my life. Their constant acceptance and love encouraged me to welcome the challenges in my life and to make the best of every situation.

My children Michael, Morgan, and my grandson Aidyn kept me going when I was not sure that I could continue. Although I was young when I first became a mother, doing so saved my life and started me on a journey beyond my wildest dreams. To them I say: I hope that seeing me reach this goal encourages you to achieve your own. I love you with my entire being. You are my life and my breath. Thank you for your patience and your sacrifices over these many years.

My best friend Kelly has remained my constant rock through everything for thirty years. She has remained by my side throughout my life, a constant guide and voice of reason.

I spent many years of my life without a partner, which often made my existence, career, and education a struggle. When I met Jeff, all of the pieces fell into place and I knew that I would spend the rest of my life with him. He is a constant source of love, strength, and peace. Our future has no bounds and I am thankful for the love and happiness that he and his children Jacob, Cody, and Alyssa have brought in to my life.

Thank you to the members of my committee for their unwavering support, Drs. Terry Lennie, Jennifer Hatcher, and Steven Fleming. I am thankful for my advisor, mentor, and committee chair Dr. Debra K. Moser. Her support and encouragement have been immeasurable. I have had unlimited opportunities to learn and experience what it means to be a nurse researcher while in the PhD program at the University of Kentucky. I was first introduced to her many years ago while I was completing my RN to BSN program at the University of Kentucky. I was considering a career in nursing research and was matched with her for my capstone project. I knew then that I wanted to return to pursue my PhD in Nursing under her guidance. She has tirelessly supported and encouraged me on this path and I look forward to many years of continued collaboration with her and the members of the RICH Heart research team.

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Chapter One

Introduction

Globally, deaths from cardiovascular disease (CVD) increased 41% between 1990 and 2013.[1] This is due in part to an increasingly large and aging global population. epidemiologic shift in the causes of disability and death from infectious diseases to chronic illnesses, and social, economic and environmental inequities.[2] Cardiovascular disease remains the number one cause of death and disability in the US[3] and in other developed countries, and has emerged as a major cause of death in developing countries.[1,4]

Cardiovascular disease risk is not uniform and disparities in cardiovascular health among vulnerable populations have been well documented.[5-7] Vulnerable populations are those who are at disparate risk of poor physical, psychological, or social health due to commonly held attributes or exposures.[8] The differential vulnerability hypothesis states that attributes, experiences, and exposures can impact some groups differently than others.[8] Differential vulnerability may be due to a compounding effect of risk and the lack of resources with which to handle them. Lack of resources may be related to social constructs such as race, physical aspects such as gender, and community aspects such as poor roads or lack of safe areas for exercise. The synergistic effects of these factors can lead to disparate CVD outcomes based on physical, psychological, and social status.

Examples of vulnerable populations include the mentally ill, prison inmates, individuals living in socioeconomically austere environments, homeless individuals, victims of violence or abuse, and those with cognitive impairment. In this dissertation, I will focus on individuals living in socioeconomically distressed rural Appalachia, prison

inmates, and individuals who have had an implantable cardioverter defibrillator (ICD) inserted. Rural Appalachians have well documented risk factors that occur more frequently than in the general population. These risk factors include tobacco use, obesity, poor diet, and limited physical activity.[9-11] The conditions in which Rural Appalachians live compound these risk factors. Many Rural Appalachians live in abject poverty, with poor roads, and limited areas for exercise.[9-11] Prison inmates are a vulnerable population due to a high burden of disease, exposure to violence, and proneness to high risk behaviors with limited personal and social resources by which to care for themselves [12] ICD recipients have higher levels of cognitive impairment than the general population and many live with the burden of anxiety and depression related to concerns regarding shock and death. This population fears the physical pain that accompanies shock but also are burdened with the fear that the device will not shock them when necessary.[13] They deal with constant reminders of mortality and multiple physical and mental comorbidities, which can impact this population physically, emotionally, and socially. These populations share common risks and exposures with limited personal and community resources for appropriate self-care, which compound to create disparities.

Disparities in CVD are well documented in vulnerable populations. The US health initiative "Healthy People 2020" defined health disparities as a "health difference that is closely linked with social, economic, and/or environmental disadvantage" and notes that "health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically

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linked to discrimination or exclusion".[14-16] Thus, health disparities go beyond simple differences in the health status of groups or specific populations. Health disparities result from systematic inequities that are unfair, unjust, and avoidable.[17] Health disparities grow from social inequalities that affect generations of populations resulting in increased risk and decreased resources across the life course based upon social stratification of groups of people.[18]

One presumed link between vulnerable populations and disparate CVD outcomes is limited health literacy[19-22] Limited health literacy is a social determinant of health (SDH), one of the few that is amenable to change. Social determinants of health are conditions in which people live out their lives,[23] circumstances that are shaped by the distribution of money, power, and resources.[23] More than 90 million Americans have limited health literacy, which results in difficulty finding, understanding, and applying information to make appropriate health care decisions and communicating these decisions to family members and healthcare providers.[24-26] Limited health literacy has been linked to poor cardiovascular health outcomes that include increased risk for cardiovascular disease (CVD),[27, 28] mortality[24, 29], morbidity,[24, 26, 30] and hospital readmissions,[24, 31] as well as decreased quality of life.[32] Limited health literacy is more prevalent in the poor,[8, 24, 33-35] elderly,[26, 36, 37] less educated,[26] minorities,[26, 38] immigrants/refugees,[39] and the chronically ill/disabled.[24] Limited health literacy in these populations may be a pathway by which health disparities are perpetuated.

Health literacy is most commonly defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[40] Health literacy is an independent

predictor of health status and it may hold stronger predictability for health status than education, socioeconomic status (SES), age, or ethnicity.[41-45] Health literacy mediates the relationship of race/ethnicity and educational attainment with self-reported health status and preventive health behaviors.[46, 47] While race/ethnicity is a non-modifiable risk factor and educational attainment in adults is a difficult to modify risk factor, health literacy is modifiable and improving health literacy may decrease CVD health disparities.[24, 48, 49]

The overall purpose of this dissertation was to explore the relationship between SDHs, particularly health literacy, and disparate outcomes related to CVD in vulnerable populations. Vulnerable populations chosen for exploration of these phenomena include Appalachian-Americans, prisoners, and ICD recipients. Race/ethnicity, geography, gender, age, multi-morbidity burden, and socio-economic status will be explored within these populations.

In the second and third chapters of this dissertation I explore the associations of gender and multi-morbidity with quality of life and psychosocial outcomes in ICD recipients in Sweden. This exploration led to the question of the impact of health literacy on these outcomes which unfortunately was not measured in the Swedish study protocol. In the remaining two chapters I explored the impact of health literacy on CVD risk in prisoners and on end of life (EOL) choices in ICD recipients, the majority of whom resided in Central Appalachia.

Disparate Circumstances: Disparate Health

Despite the steady decline in average overall CVD deaths in the US since the 1960s, it remains a heavy societal burden with the high cost of treatment, the loss of

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productivity, and premature deaths. The cost of CVD in the US for 2015 was 320.2 billion dollars.[3] In 2015, CVD was the cause for approximately one in every three American deaths.[3] However, CVD and related outcomes are not decreasing at the same rate for all. According to the American Heart Association,[3] age adjusted death rates for African-Americans are 33% higher than for Caucasian-Americans. The prevalence of CVD also increases as one creeps closer to the poverty line in America,[50] a finding which echoes the classic Whitehall study of Sir Michael Marmot.[35] Poverty has a dose dependent relationship with CVD prevalence in the US (See Table 1.1.) The relationship between poverty and CVD is apparent in the Appalachian region of Kentucky, the poorest area of America with the highest rates of CVD and common CVD risk factors including diabetes, obesity, physical inactivity, and smoking.[51] Kentucky ranks consistently within the top ten for having the worst health outcomes in the U.S. with the Appalachian counties ranking the worst within the state.[51]

Table 1.1 Age adjusted percentage of selected circulatory diseases among adults 18 and over in the US: 2012*[50]				
Heart Disease				
Poverty Status**	All Types	Coronary	Hypertension	Stroke
Poor	14.0 (0.69)	9.8 (0.61)	29.5 (0.71)	4.8 (0.38)
Near Poor	12.6 (0.48)	7.7 (0.38)	27.1 (0.69)	3.7 (0.27)
Not Poor	9.9 (0.25)	5.2 (0.19)	22.3 (0.35)	1.9 (0.11)

* Results in table are presented as % (standard error)
** **Poor** persons are defined as having an income below the federal poverty threshold.
   Near poor persons are defined as having an income 100% to less than 200% of the federal
   poverty threshold. **Not poor** persons are defined as having an income that is 200% of the
   federal poverty level or greater.				

Appalachia is comprised of portions of 13 contiguous Eastern states in the United States, including 54 Kentucky counties. These 54 Eastern Kentucky counties are the heart of the Central Appalachian region, which encompasses counties in Kentucky, West Virginia, and Tennessee. This region is well known for having the nation's worst social,

environmental, and health conditions. It has been called a "third world country" within the United States.[52]

The Appalachian Regional Commission utilizes an index based, county level economic classification system for the measurement and monitoring of the economic status of the region. Each county's mean three year unemployment rate, per capita market income rate, and poverty rate are compared to the national average for an index score in each of the categories. These scores are then summed and averaged for an overall county level index score. This county level index score can then be compared to any county in the US. Counties can then be designated as distressed, at-risk, competitive, or attainment based on this score. These rankings are revised annually by the agency. For fiscal year 2015, all 54 counties of Kentucky in the Central Appalachian region were designated as distressed or at-risk. No counties reached the levels of attainment or competitive[10] and nearly one third of the 100 poorest counties in the US were located in Kentucky.[53]

Due to the continuing out-migration of college age and young adults, individuals over the age of 65 make up the greatest majority of people living in Central Appalachia. Low educational attainment is an issue in the region, where approximately 25% of Central Appalachians have attended college compared to 50% of the rest of the nation.[9, 52] Personal income and average salaries in Central Appalachia were 20% lower than the national average in 2007 with 67% of counties with levels of unemployment higher than anywhere else in the country[9]. Many younger workers in the area are leaving to find better opportunities for employment resulting in the graying of Appalachia.[11]

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Another US population group with alarming health disparities is the prison population. The US imprisons more of its populace than any other nation in the world. In 2001, more than 4.3 million US residents were former prisoners.[54] This is particularly alarming as African American males in the US are disproportionately imprisoned. One in 17 Caucasian white men are incarcerated in their lifetime, compared to one in six Latino men, and one in three African American men.[54] The overall incarceration rates for 2010 indicate that 380 Caucasian, 966 Latino, and 2,207 African-Americans per 100,000 people in each group were incarcerated.[55, 56] African-Americans make up 16% of the general US population[57] while the population of the US prison system is made up of 37.4% African-American.[58]

A criminal history is damaging for these men and perpetuates health disparities that develop in prison or were present prior to imprisonment. A criminal history makes it difficult for former inmates to find jobs when they leave the prison system that can adequately support them and their families, often perpetuating the cycle of incarceration. The loss of status related to a felony conviction leads to the disenfranchisement of a large number of citizens, leaving 1 in 13 African-Americans unable to vote and find adequate health insurance coverage through employment. Once a person enters the state prison system the chance of recidivism is high, reportedly 76.6% within five years.[59]

The leading cause of death in prisoners is CVD. Biswanger et al.[60] found that within two weeks of release from a Washington state prison, former inmates had an age adjusted death rate 12.7 times that of other residents. The deaths were attributed to drug overdose, CVD, homicide, and suicide. Many of these preventable deaths were related to

a violent history or drug use, but a lapse in treatment for chronic health conditions underlies many CVD and infectious disease deaths in this population.

The ICD is the treatment of choice for individuals at high risk for sudden cardiac arrest. These devices were previously used for people who had a history of arrest, but over the past two decades the use of ICDs as a tool for primary prevention of sudden cardiac arrest has risen and the majority of individuals now have the device placed for this reason.[3] Most ICD recipients adjust psychologically to the devices within the first year following implant, but approximately 20% of recipients experience significant levels of anxiety and depression after the adjustment period.[61, 62]. This is important because anxiety and depression impact the overall quality of life in this population, particularly in women.[61, 63] High levels of physical and psychological comorbidities are common in this population and place them at a high risk for poor outcomes related to CVD with often lower than average resources to offset the imbalance of risk.

Limited health literacy: A modifiable social determinant of health

The most commonly used definition of health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions"[40] does not fully describe the phenomenon of health literacy. This definition is limited as it refers to choices made within the context of the healthcare system and is often used for the exploration of patient adherence to prescribed treatment regimens.

Nutbeam[64] identified this limitation and named three distinct levels of health literacy: functional, communicative, and critical. Functional health literacy is the ability

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to apply literacy skills to function effectively as a patient within the health care system measured by the ability to read, follow directions, and adhere to a plan of treatment. This level of health literacy implies a dependent relationship with the healthcare provider. Communicative/Interactive health literacy implies an equal relationship between the patient and healthcare provider in which ideas are discussed and information is supplied. Critical health literacy implies a relationship in which the patient and the HCP discuss ideas and risks/benefits are weighed with the ultimate decision resting in the hands of the patient. These three levels occur in a hierarchical manner as individuals develop health literacy, each level building on skills developed in the previous. Critical health literacy is key to empowerment of a patient and full participation in the patient healthcare provider relationship. Health literacy research is fairly young, having begun in earnest in the late 1990's. The concept continues to evolve and as it does, so do the instruments created to measure it.

The conceptual definition of health literacy used in this dissertation was "the cognitive and social skills which determine the motivation and ability to gain access to, understand, and use information in ways which promote and maintain good health".[65] Of the many definitions of health literacy available, this one was chosen because of its comprehensiveness and inclusion of cognitive and social skills, as well as motivation, and information seeking. When compared to other definitions this one is global in its scope as many others confine health literacy to its use in the American healthcare system.

Health literacy is a topic that began receiving recognition as a SDH in the 1990s. There was and continues to be confusion among researchers regarding the concept of health literacy as a separate and distinct concept from print literacy. [66] Early researchers

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did not often differentiate between print literacy in the health setting and health literacy. While print literacy is one of the domains of health literacy, the latter concept also includes the following other attributes, numeracy skills, information literacy, and oral literacy, which are used to synthesize and apply information related to health care decisions as health literacy.[26] Health literacy is a critical juncture between health education and decision-making. Without adequate levels of health literacy individuals cannot fully engage in self-care or make appropriate decisions about their health and well-being.

In a review of current research in health literacy, Sorenson et al.[67] discussed the lack of consistency in which health literacy has been defined among researchers and authors. The authors point to 17 different definitions and 12 conceptual frameworks as evidence of this inconsistency. Westlake et al.[66] determined that there have been four consistent components of health literacy identified across published definitions and conceptual frameworks including: print literacy, numeracy skills, information literacy, and oral literacy. These factors come together with analysis and communicative abilities to form health literacy.[26] Westlake et al.[66] present a model of health literacy based on a systematic review of the literature of health literacy by Paasche-Orlow et al. [26] as the most complete conceptual framework to date (See fig. 1.1).

Figure 1.1. Conceptual model of health literacy[66]

Health Literacy

Print Literacy | Oral Literacy | Information Literacy | Numeracy

Critical Analysis

Communicative Abilities
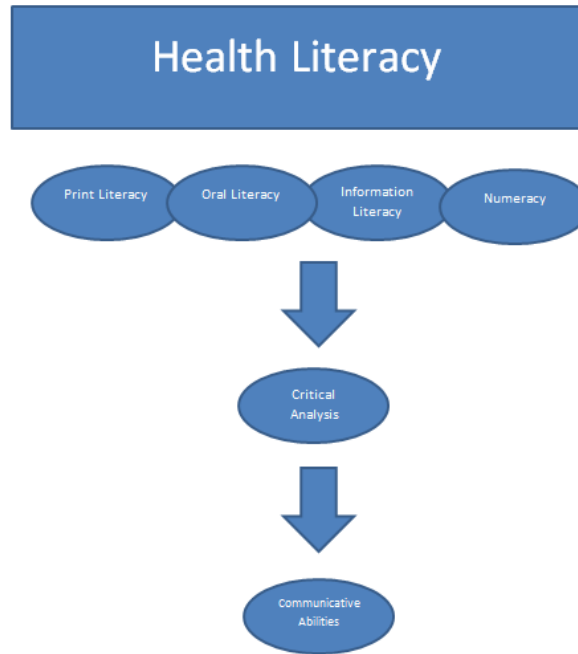
Westlake et al's.[66] conceptual definition includes not only the ability to perform skills necessary for each of the types of literacy, but a required level of cognition that provides the individual with the ability to critically analyze information and the ability to communicate expressively (speaking) and receptively (listening). While this conceptual definition is entitled functional health literacy, it incorporates the three levels of health literacy identified by Nutbeam[64] including functional, communicative, and critical analysis abilities. It should therefore be seen as a definition of overall health literacy. A full understanding of the concept of health literacy is necessary to understand how it impacts health outcomes. A full definition and examples of each variable of the concept was explored.

1. Print literacy is the ability to read and understand written materials and is an essential skill needed to assimilate information in the health care setting. Documents such as patient teaching materials, informed consents, and explanations of insurance benefits are key to patient understanding of healthcare, yet many of these documents are written at reading levels that surpass the average American's ability.[24, 68] The inability to read such documents renders individuals incapable of fully understanding and participating in complicated treatment regimens and procedures. There are feelings of shame associated with the inability to read or to read at the level required for most health related documents and often people will not share that there are problems understanding the material.[24, 66, 69]

2. Oral literacy is the ability to communicate information related to health with healthcare providers and family members. The skill incorporates both verbal and aural skills[70] which are necessary to listen to information provided by others and to express one's symptoms, needs, and decisions (expressive and receptive communication respectively).

3. Information literacy is the ability to realize the need for information, to locate and critically analyze appropriate resources. [71] American society is inundated with health information at an increasing pace. Web pages, television advertisements, and advice from healthcare providers, and well-meaning friends are just a few examples of the health information available to individuals. The ability to find and determine if information is valid, reliable,

and appropriate is an important skill, necessary for making decisions regarding one's health.

4. Numeracy is the capacity for quantitative thought and reasoning.[72] Numeracy skills are imperative for a patient to understand mathematical concepts such as risk, medication adherence, and calculation of sliding scale medications, such as insulin or diuretics.[66] The inability to perform numeracy related activities puts individuals at risk for uninformed consent, unnecessary procedures, and non-adherence to prescribed treatments.

5. The ability to critically analyze information is dependent upon both cognitive and personal attributes. Individuals with decreased capacity due to age or chronic disease may have difficulties understanding and applying health information.[36, 37]

6. Individuals must be able to physically communicate their needs and choices. This requires the physical ability to speak, listen and/or write. Individuals with disabilities or who do not speak English need specific interventions, such as communication boards and interpreters, to ensure that they fully understand the health information given to them by healthcare providers.

This analysis of the concept of health literacy is by far the most complete found in the literature to date and it was used in the studies reported in this dissertation. It is important for the purpose of this dissertation that the concept of health literacy be fully and succinctly defined as there has been much confusion in the literature and among healthcare providers regarding this concept.

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Causal Pathway Between Health Literacy and Disparate Cardiovascular Outcomes

Paasche-Orlow and Wolf[73] presented a conceptual framework identifying the following three pathways by which health literacy impacts health outcomes: 1) access to and utilization of healthcare; 2) provider-patient interaction; and 3) self-care. Each of these pathways includes individual and external factors that are affected by health literacy and contribute to health outcomes (See Fig. 1.2). This conceptual framework was utilized throughout the studies reported in this dissertation as a causal pathway by which health literacy impacts disparate health outcomes in vulnerable populations.

Figure 1.2. Pathways linking limited health literacy and health outcomes[73]
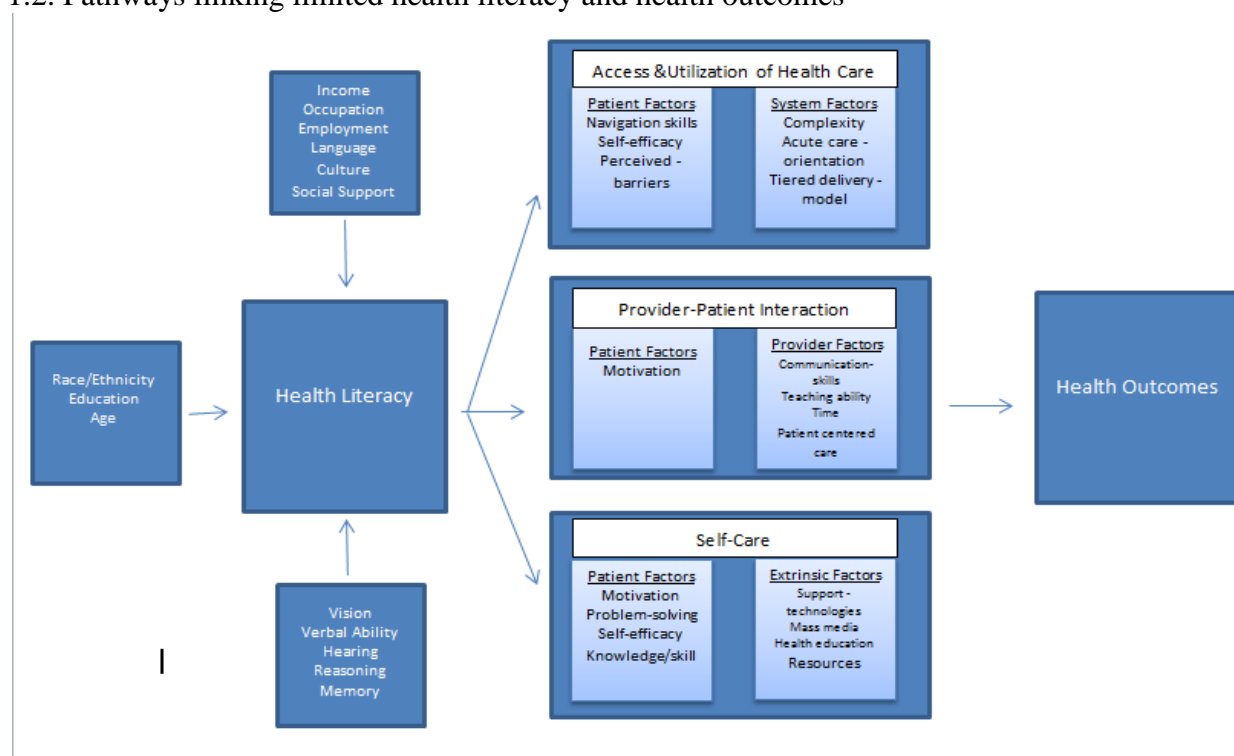
Health literacy is influenced by social, personal, and physical abilities. Each of these variables can act in a manner that increases or decreases one's ability to use health information to make informed choices. The studies reported in this dissertation will

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explore each of these variables and how they impact health literacy in Appalachian Americans, prisoners, and ICD recipients.

Appalachia. In Central Appalachia, levels of income and employment are among the lowest in the country.[9, 11] Counties within the region provide little opportunity for employment with the exception of coal mining. As the country moves away from dependence on fossil fuels, this enterprise becomes less lucrative and is a dangerous profession. Coal miners have high levels of chronic heart and lung diseases due to exposure to coal dust, smoke and other environmental pollutants, along with a high rate of CVD risk factors that affect both heart and lung health .[74, 75] Little education is required for these positions and Appalachian men often leave school early to work in the mines. [11]

Language and culture affect health literacy in in Central Appalachia. Culturally, Central Appalachians believe in developing relationships with outsiders very slowly.[76] This presents a difficulty in a health care system that moves very rapidly. There is little time in the current health care delivery system for physician and patient interaction and this can be difficult for people who spend time with small talk to develop a relationship before divulging important clinical information. Social support in Central Appalachia revolves around faith and family. Strong familial ties are characteristic of the region. Extended families provide support emotionally, physically, and financially.[76] Churches are often the center of the social life in the counties.

Financial support for schools through taxation is lacking in Central Appalachia as the tax base is low due to decreased levels of income and employment in the region. This

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reality negatively affects the quality of schools in the region. It can be difficult to recruit teachers to work in this area because of the often substandard wages, living, and teaching conditions in the area. Many individuals who leave Central Appalachia to attend college do not return, creating an educational vacuum in the area.[11] The vast majority of the Central Appalachian is Caucasian, and over 65 with low levels of educational attainment.[11]

Prison Inmates. Prisoners lose many of their social support mechanisms once incarcerated. They are no longer employed outside the prison and often have little to no income. They may have little or no contact with their families. Their physical needs are provided for by local, state, or federal governments. The language and culture of the prison system is vastly different than that outside the prison walls. Health care providers must understand the system in which the prisoners live to develop a relationship that allows for the exchange of important clinical information. Prisoners are often hesitant to report drug use, violent behavior, or sexual encounters for fear of punishment from the administration of the institution.[60] This strained process and lack of trust may make communication difficult between prisoners and healthcare providers, resulting in an incomplete clinical picture leading to continuing high risk behaviors and missed opportunities for health promotion.

ICD Recipients. Approximately 35 to 40% of ICD recipients will experience a shock from their device.[77, 78] Many ICD recipients do not fully understand the function of the device and assume the device is solely beneficial,[79, 80] few can discuss the risks associated with implant including infection, psychological maladjustment, inappropriate shocks, shock storms, device malfunction, and device recalls.[80] Device therapy requires a

significant commitment on the part of the recipient for achieving the best physical and psychological outcomes.

Access and Utilization of Healthcare

Maneuvering within a complex healthcare system can be a difficult task requiring skills on the part of the patient. Without the ability to critically analyze information received through, print, information, and oral literacy and communicate needs, the individual will not be able to navigate the healthcare system effectively.[81] The individual with limited health literacy may not be able to read signage in the hospital or calculate appointment dates, resulting in missed appointments for consults, follow-ups, or diagnostic testing. This is sometimes perceived as non-compliance by the healthcare provider, who in turn may not be willing to work harder to communicate information to a patient they believe lacks motivation to participate in a treatment regimen. Individuals with limited health literacy often may not have confidence in their ability to perform these functions and avoid the healthcare system altogether.[81]

Limited health literacy is associated with decreased use of preventive health services,[82] and increased use of emergency services,[83, 84] hospitalization,[32, 38] and re-admission.[24, 85] The current health care delivery system is focused on acute care and if individuals are unable to access the appropriate provider for the level of care they need, they will access whatever services are available, resulting in higher costs, fragmented care, and poor outcomes.[84, 86-88]

For Appalachian Americans, access to hospitals and healthcare providers is limited, Many have to travel more than two hours by vehicle to access health care

facilities.[11] This can result in underutilization of healthcare; this process is burdensome to individuals and their families and is often reserved for only the gravest of illness. Preventive healthcare is often foregone due to the difficult nature of access to healthcare providers and the lack of providers in rural areas with a preventative focus. There are limited hospitals in the region, mostly critical access hospitals that are not capable of providing high level acute care.[11] This results in individuals seeking care only in a crisis situation in an unfamiliar environment. Way finding in the hospital may be difficult due to the use of unfamiliar words and a foreign environment.[24, 48] The closeness of families is not often recognized by hospital administrations as essential and when ill, Appalachian Americans may not have the benefit of their tight knit families, resulting in a lack of social support. Access to health care providers is also limited, as there are few primary care doctors who choose to practice in rural areas. Many of those who do, often speak English as a second language, resulting in a language barrier. Individuals at risk have identified this communication difficulty as a barrier to relationships with the few primary care physicians that do practice in rural areas.[89] These cultural and language barriers can have a great impact on health literacy in this population, resulting in decreased access to and utilization of health care services.

In the 1976 Estelle vs. Gamble Supreme Court decision[90] appropriate medical care was mandated for prisoners, and they are the only group in the United States for whom healthcare is federally mandated. Prisoners often have their first interaction with the healthcare system when incarcerated, and 80% of inmates with chronic illnesses such as CVD, HIV/AIDS, diabetes mellitus, and hypertension, or had not received routine care before entering the prison system.[91] Prior to incarceration, most inmates reported having

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used the local emergency room for primary care purposes.[91] Despite the access to healthcare given to prisoners, such healthcare is not optimal and is not preventative focused. Most prisons continue to use an acute "sick call" model of healthcare. Prisoners are seen based on their initiative to contact the healthcare providers for their acute needs. This type of care is not conducive to treatment of chronic physical or psychiatric disease.[92] More than 95% of prisoners return to their communities following release from prison.[93] It is imperative that prisoners receive appropriate treatment for chronic illnesses while incarcerated in order to decrease the burden on the community once released. Currently, little medical information is transferred between healthcare facilities and correctional institutions[92] resulting in fragmented care for these individuals.

Current guidelines recommend follow-up visits should occur for ICD recipients approximately every three to six months. These frequent interactions with the healthcare system can prove difficult for some, particularly those with limited social resources, causing missed appointments. Individuals may be considered non-adherent to a treatment protocol if appointments are missed, which can impact the relationship between the recipient and healthcare provider.

Provider-Patient Interaction

The healthcare environment is not limited to facilities, but includes personal interaction with a healthcare provider. Limited health literacy can affect these interactions in many ways.[94] Appropriate communication skills are required of both the patient and the healthcare provider. Healthcare providers must create a non-judgmental environment allowing ample time for patients to ask questions and provide patient centered care in a

culturally competent fashion.[95] Proper training and skills are necessary for healthcare workers to provide appropriate patient centered care.[96] All healthcare providers should be aware of the limitations of their patients and implement interventions to ensure that the patient understands the information that the provider has conveyed.[97]

Appalachian American culture dictates that a personal relationship be developed with healthcare providers prior to divulgence of personal and health information. Often, family members are involved in the decision making process.[76] It is important that healthcare providers recognize the cultural implications of interactions with this population when providing healthcare. Information must be presented in a format that is amenable to cultural and educational status. Appalachian Americans may often appear stoic, and pride in self-sufficiency is often characteristic of these individuals.[76] Ample time for discussion of issues with these individuals should be included in the plan of care.

Prisoners are often distrustful of authority figures. Relationships need to be cultivated with care. Depending upon the amount of time spent in an institution, it may be difficult for prisoners to make and communicate decisions regarding healthcare, resulting in impaired health literacy.[98-101]

Self-Care

Self-care is an important aspect of CVD prevention and management. Limited health literacy can impact self-care in many ways. Knowledge of one's CVD or risk for CVD is needed to fully understand necessary lifestyle changes, recognize worsening symptoms, and determine when to contact the healthcare provider for assistance.[102, 103] Limited health literacy is associated with decreased knowledge and can impact self-care

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and cardiovascular health outcomes for individuals.[104, 105] The ability to fully engage in self-care requires problem solving and reasoning skills. Individuals with limited health literacy may have difficulty with these tasks. Healthcare providers should determine the level of health literacy of all of their patients in order to determine if there may be some issues with the ability to care for one's self.

For many Appalachian Americans, Christian faith is a cornerstone of their value system. Belief in the afterlife and pre-destination can impact health literacy and health behaviors. This is can be seen in the concept of fatalism. The belief that the one's time of death is fore-destined and that lifestyle change will not impact health is a common one. [76, 106] This can create difficulty when counseling patients to make changes. Discussing change within the context of values is an important skill of the healthcare provider. Allowing patients to verbalize their beliefs and discussing their decisions with these beliefs in mind can encourage trust and help to build important relationships.[76, 107]

Despite this difficult barrier, Appalachian Americans often are self-sufficient and have problem solving skills born out of necessity. Strong familial ties in the region encourage individuals to make changes to take care of others and this motivation can be powerful. Due to lower levels of educational attainment, the knowledge and skills needed for self-care can be lacking. Targeted health education can remove this barrier and provide confidence in the ability to care for oneself. Overcoming these specific barriers to health literacy and self-care in Appalachian Americans may result in better CVD outcomes.

Prisoners also often have an external locus of control that may impact health literacy levels. Years of institutionalization can challenge one's belief that individual change can make a difference in health and wellness. Problem solving skills and self-efficacy may be limited due to institutionalization.[98, 100, 101] Provision of health education should include an emphasis on the importance of individual change and an internal locus of control related to health issues as well as knowledge based information on how to prevent risk and promote health.[100, 101]

Impaired health literacy impacts the self-care of ICD recipients in multiple ways. Many ICD recipients have impaired knowledge regarding the function of their device, which affects decision-making, adherence to treatment regimens, and recognition of symptoms requiring an intervention.[108] Many ICD recipients are unaware of the risks associated with the device and the implant procedure, which results in alarming misconceptions.[109]

Vulnerable populations, such as Appalachian Americans, prisoners, and ICD recipients exhibit disparate CVD health outcomes. These populations have also been identified at a high risk for limited health literacy due to social and personal characteristics. In this dissertation I examined the link between SDH, health literacy and disparate CVD outcomes in Appalachian Americans, prisoners, and ICD recipients.

Summary of Subsequent Chapters

The SDH impact CVD outcomes in vulnerable populations. The studies I reported in this dissertation explored these factors and the effect of health literacy levels on CVD related outcomes. Passche-Orlow and Wolf's[110] conceptual framework provided an

outline for this purpose. The factors discussed in this conceptual framework were used to guide the study designs, data collection, data analysis and interpretation of the results.

Chapter two was the report of a cross-sectional study in which QOL, anxiety, and depressive symptoms were compared between genders in 3,067 ICD recipients in the Swedish ICD and Pacemaker Registry. Multiple linear regression was used to determine predictors of anxiety, depression, and QOL in ICD recipients. This study was important because examination of anxiety, depression and decreased QOL in ICD recipients has been limited to date. ICD recipients have risks and limited resources that are different from individuals with other types of CVD. Many types of CVD, such as heart failure and ischemic heart disease can lead to the need for a device but there are other disease processes that can lead to device implant such as hypertrophic cardiomyopathy and congenital or genetic heart disease that makes the population differ from others, as these conditions often occur in younger populations.

Chapter three was the report of a study in which the association between multi-morbidity burden and QOL was examined in 3,067 ICD recipients in the Swedish ICD and Pacemaker Registry. Logistic regression was used to determine predictors of QOL. This study was important as it examined the relationship between physical and psychological comorbidities in ICD recipients and QOL. As stated previously, many ICD recipients misunderstand the function of the device and are unaware of the impact that the device may have on their lives overall. ICDs are sometimes implanted in individuals who do not meet the current guidelines for treatment and conversely not implanted in individuals who may benefit greatly from the devices.[3, 111] This chapter highlights the importance of open and frank discussions with patients prior to and throughout the

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trajectory of device therapy, and discusses the need for appropriate referrals to cardiology and electrophysiology by primary care providers.

Chapter four was the report of a study conducted to determine whether health literacy levels independently predicted cardiovascular risk in the male prison population. Non-linear regression was utilized to address this purpose. Prisoners are at risk of CVD in general due to high risk behaviors and socioeconomic circumstances. Impaired health literacy is a SDH of health that is amenable to change and can be addressed within the prison system fairly easily to potentially decrease the risk of CVD in this population. This study highlights the importance of risk recognition in the vulnerable prison population and sets the stage for future studies in this high risk group.

Chapter five was the report of a study in which the relationship between health literacy and decisiveness regarding end of life (EOL) choices was examined. Multinomial regression was used to determine predictors of decisiveness regarding EOL choices. This study was important as documented misconceptions regarding device therapy may impact the choices people make regarding defibrillation therapy withdrawal and generator replacement in the context of terminal illness. These misconceptions may put ICD recipients at high risk for unnecessary and painful shocks during the active dying process, leading to disparities in QOL and the quality of the death experience.

Chapter six was the report of a study in which the social conditions and clinical differences between ICD recipients residing in the Central Appalachian region of Kentucky and other areas of the state were compared. The relationship between SDH and perceived poor health status was then examined. This study highlights population

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differences that may contribute to the explanation of disparities in health outcomes for ICD recipients in Central Appalachia.

Chapter seven is the integration of the previous chapters and a further examination of the link between social determinants of health, particularly health literacy, and health disparities related to cardiovascular health in vulnerable populations. The mechanism of association between limited health literacy and disparate CVD related outcomes in vulnerable populations was explored. Appalachian-Americans, prisoners, and ICD recipients were chosen as index groups in which to determine the links between health literacy and health disparities in vulnerable populations due to well-known CVD disparities. Race, geography, gender, age, and socio-economic status were explored within these populations and health literacy as a mitigating factor of poor CVD related health outcomes.

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Chapter Two

Gender Disparities in Symptoms of Anxiety, Depression and Quality of Life in

Defibrillator Recipients

Introduction

The implantable cardioverter defibrillator (ICD) is the treatment of choice for primary and secondary prevention of death from lethal ventricular arrhythmias.[1-3] Approximately 20-30% of ICD recipients are women, and there are a number of well documented gender disparities surrounding the use of ICD therapy.[4, 5] Although mortality outcomes appear to be similar between the genders, women receive appropriate ICD therapy less often than men, have worse functional status at ICD implantation, and have higher rates of adverse events in the hospital after ICD implantation.[5-8]

The majority of ICD recipients fare well psychologically following device implantation. However there are a significant number of ICD recipients who experience symptoms of anxiety and depression which can result in decreased quality of life.[9] Psychological distress can vary based upon: clinical factors, the context of device implant; specifically whether or not the device was implanted following sudden cardiac arrest, time since implant, and the experience of complications and /or shocks.[9-11] Dunbar et al.[9] presented a model of the ICD recipient trajectory that breaks the patient experience into three major categories: pre-implantation, post-implantation with early recovery and adjustment phases, and end of life. Each of these categories includes events, treatments, and potential complications that can impact the psychological wellbeing and the quality of life of the ICD recipient.

Psychological Distress in ICD Recipients

The psychological response and adjustment to ICD implant is complex and multifactorial. Magyar-Russell and colleagues[12] presented a review of 45 studies regarding the prevalence of anxiety and depression in adult ICD recipients. Of the 45 studies, 31 measured depression and anxiety 12 months or more following implant (adjustment phase) with a range of 12-645 participants, only three of these 31 studies had greater than 200 participants.[13-15] These studies found the prevalence of psychological distress to be higher in ICD recipients than in the general population with the prevalence of symptoms of anxiety 15-19% (CI11-22) and depression 11-18% (8-21).[12-15] These levels are consistent with other studies that report levels of depressive symptoms in chronic cardiovascular disease.[16, 17]

Circumstances surrounding the implant of an ICD can impact the manner in which individuals adjust to the device and affect levels of psychological distress following implant.[14, 18] Individuals who require an ICD following a sudden cardiac arrest may experience post-traumatic stress disorder (PTSD) from resuscitation efforts and device implant.[19] Levels of PTSD, reported to be higher in female ICD recipients,[20] may affect the amount and severity of symptoms of anxiety and depression.[19]

Appropriate adjustment to device implant and freedom from psychological distress following the implant of an ICD may depend in part upon whether or not shocks have been delivered by the device[21, 22] These devices can be anxiety provoking as recipients may worry about the device delivering therapy and causing pain or worrying about the device not functioning properly resulting in a sustained lethal arrhythmia.[21, 23]

The presence of comorbidities has been shown to have a negative impact on the psychological well-being of ICD recipients.[24] Reports from the US National ICD Registry indicate that for the years 2010 and 2011, 82.5% of ICD recipients reported comorbid heart failure.[25] With approximately 58% of individuals diagnosed with heart failure reporting five or more comorbidities,[26] the impact of of such on the psychological wellbeing of ICD recipients should be explored.

Gender Differences and Psychological Distress in ICD Recipients

The occurrence of gender differences in psychological outcomes in ICD recipients remains unclear. [20, 27-29] Recent studies have been limited by small numbers of female participants. The average percentage of male participants in recent ICD studies is approximately 80-90%,[12] making gender comparisons difficult.[21] This is due in part to the overall ICD population, in which women do not have devices implanted at the same rate as there male counterparts.[4, 30-32]

A review of the recent literature quickly determines that the issue is far from clear. Multiple studies report no gender difference in depression[28, 33, 34] or anxiety[10, 20, 28] among ICD recipients. These results however are contradicted by studies that report increased depression[20, 35] and anxiety[33-35] in female ICD recipients independent of other variables. The contradictory results in the most recent studies are reported from data in larger sample populations overall, however the number of women represented in the samples are still low making the comparison of outcomes related to gender differences difficult. Studies that focus on gender differences, etiology and consequence, are lacking in both number and quality.

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In a recent meta-analysis, investigators were unable to confirm whether gender differences in psychological status did exist and they strongly recommended that adequately powered studies be conducted in order to make a reliable determination.[29] Accordingly, we conducted a nationwide study of ICD recipients that was adequately powered to compare quality-of-life, anxiety and depression symptoms between the genders. We also sought to determine predictors of each of these variables in men and women. In addition to socio-demographic (i.e., age, living arrangement, and educational level) and clinical predictors (i.e., comorbidities, indication for ICD implantation, type of ICD, battery replacement, time in years since implantation, perceived quality of the overall ICD experience, and whether ICD shocks had been experienced)[22] identified from the literature as potential covariates, we included other psychosocial (i.e., type-D personality, perceived control, and social support) and cognitive (i.e., knowledge of the ICD) predictors likely to be associated with symptoms of anxiety, depression and quality-of-life.[36-38]

Methods

Study Design, Sample and Data Collection

This correlational study received ethical approval from the Regional Ethics Committee for Human Research at the University of Linkoping, Sweden. Included in this study were all adult patients who were in the Swedish ICD and Pacemaker Registry in 2012 who had had an ICD or cardiac resynchronization therapy with defibrillator (CRT-D) implanted for at least one year. [39-42] Potential participants were mailed an invitation to participate. There were no additional inclusion or exclusion criteria except willingness to return the signed consent document and completed questionnaires.

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The Swedish ICD and Pacemaker Registry is a national database that has been in place since 1989. All patients who have had a cardiovascular implantable electronic device placed in Sweden are followed in this registry. In 2012, 5,535 adult patients were eligible to participate and asked to do so by mail during September to October 2012. Patients were provided with stamped return envelopes. One mailed reminder was sent out 3-4 weeks following the first mailed invitation.

Measures

Psychosocial measures

Anxiety and Depression

The Hospital Anxiety and Depression Scale (HADS) was used to measure symptoms of anxiety and depression.[43, 44] The HADS is a 14-item instrument that includes two subscales that measure anxiety and depression. Each subscale is composed of 7 items. Scores on each subscale range from 0 to 21, higher scores reflect higher anxiety or depression. The reliability and validity of the HADS has been demonstrated across multiple cultures, including Sweden.[40] A cut off value of ≥ 8 for each construct has been identified for use in categorizing patients as having symptoms of anxiety or depression.

Quality-of-Life

Quality-of-life was measured using the EuroQol-5D (EQ-5D).[45] The EQ-5D is a standardized instrument for the measurement of health-related quality-of-life. Patients respond to items by answering from the perspective of whether the item is associated with no problems, some problems, or severe problems. Given the number of items and possible responses, there are a total of 243 possible health states combinations, each of

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which is referred to using a five-digit code, using the numbers 1 to 5. The five-digit code is then converted into a single mean index. The EQ-5D scores can range from 1.0, which reflects the best quality-of-life to -.59, which represents the worst quality-of-life. In Sweden, the UK EQ-5D index tariff is used to obtain quality adjustment weights (index score).[46] The EQ-5D has been used extensively in cardiovascular research and has been shown to have good validity and reliability.[47-50]

Type-D Personality

A type-D personality is considered a distressed personality that consists of the following two relatively stable traits: negative affectivity, and social inhibition. The 14-item Type-D Scale (DS14) was used to measure a distressed personality.[51] There are seven items each that assess negative affectivity (e.g., "I often feel unhappy") and social inhibition (e.g., "I am a closed kind of person").[51] This instrument was developed among a cardiac population and has well-established reliability and validity.[51] Scores from both subscales are combined and a standardized cut-point ≥ 10 identifies a type-D personality.[51]

Social Support

Perceived social support, a subjective sense of support from family, friends, and significant others, was measured using the Multidimensional Scale of Perceived Social Support (MSPSS).[52] The MSPSS consists of 12 items which cover three dimensions; Family, Friends and Significant others. Each item is rated from 1 to 7. A total score is calculated by summing the results for all items. The possible score range is between 12 and 84, the higher the score the higher the perceived social support. In addition, separate subscales can be used by summing the responses from the items in each of the three

dimensions. The possible score range for the subscales is between 4 and 28.[27] The

reliability and validity of this instrument were supported by previous studies,[53, 54]

including among European patients.[38, 55] A previous Swedish study suggested that it was

preferable to use the three subscales versus the total score. However, in this study, the

results were the same with both methods, so we present only the results using the total

score.[55]

Perceived Control

Perceived control was conceptualized as an individual appraisal of valued aspects

of life being manageable or being managed.[56] The 4-item, Control Attitudes Scale was

used to measure perceived control.[57, 58] This instrument has been validated in a Swedish

cardiac population and adequate reliability was demonstrated.[57] Higher scores indicate

greater perceptions of control.

ICD Knowledge

Data on ICD Knowledge was collected using the Experiences, Attitudes and

Knowledge of End-of-Life Issues in Implantable Cardioverter Defibrillator Patients

(EOL-ICD) Questionnaire.[41] The EOL-ICDQ was originally developed and tested for

content and construct validity and for homogeneity and reliability in a Swedish setting,

with the internal consistency being 0.70 and the item difficulty index varying between

0.30 and 0.88. Respondents are presented with 11 statements concerning ICD treatment

at the end-of-life: three items on ethical aspects, two items on the function of the ICD,

and six items on practical consequences associated with ICD deactivation. The

questionnaire involves questions such as "Turning off the defibrillating shocks in an ICD

is the same as active euthanasia" (i.e., a false statement), and "An ICD always gives

defibrillating shocks in connection with end-of-life" (i.e., a false statement) and the respondents list their answer as "true/false", or "don't know". Correct responses receive a score of 1, incorrect responses and "don't know" responses receive a score of 0. Total possible highest score is 11.

Sociodemographic and clinical variables

Sociodemographic variables collected included gender, age, living arrangement, and educational level. Information on clinical variables including: comorbidities, indication for ICD implantation, type of ICD (CRT-D vs. ICD), battery replacement, and time in years since implantation were obtained from the Swedish ICD and Pacemaker Registry. Clinical data on perceived quality of the overall ICD experience, and whether ICD shocks had been experienced were obtained through investigator-designed questions. Perceived quality of the overall ICD experience was rated by patients on a one to four scale with one equaling "very good" and four equaling "very bad'. ICD shock experience was determined by one item with the following three options: once, several times or no. Comorbidity data was self-reported by the participants from a provided list of comorbidities which included both cardiac and non-cardiac comorbidities.

Statistical Analysis

All analyses were conducted using SPSS, version 17. Characteristics were compared between men and women using independent t-tests and chi-square. Multiple linear regression analyses were conducted in order to determine predictors of symptoms of anxiety, depression and quality-of-life in men and women separately. Predictors used were socio-demographic (i.e., age, living arrangement, and educational level), clinical predictors (i.e., comorbidities, indication for ICD implantation, type of ICD, battery

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replacement, time in years since implantation, perceived quality of the overall ICD experience, and whether ICD shocks had been experienced), psychosocial (i.e., type-D personality, perceived control, and social support), and cognitive (i.e., knowledge of the ICD) characteristics. We entered these grouped predictors in steps to determine the contribution of each group to the explanation of the variance in anxiety, depression and quality-of-life.

Results

Background characteristics

Total Sample.

Of the 5,535 patients who were mailed the survey, 3,067 patients completed it for a 55% response rate. This survey was completed by 55% of the total population of ICD recipients in Sweden. Of these, 2,771 had data on the variables used in this analysis (Table 2.1). There were no differences in patient characteristics between those 2,771 with and those 296 without the variables of interest. The mean age of the overall sample was 66 ± 12 years with a range of 19 to 94 years. Time since implantation ranged from one to 23 years with a mean of 4.7 ± 3.9 years, 23% had a CRT-D implanted, 64% had devices implanted for secondary prevention of sudden cardiac arrest, and 25% had previously undergone an elective battery replacement.

Comparison of Sociodemographic, Clinical, and Psychosocial Characteristics between Women and Men.

We enrolled 20% women and 80% men, and the genders differed on multiple characteristics (Table 2.1). Women in the sample were significantly younger than men, had a longer ICD implantation time, more often lived alone, had a higher level of

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education, more often had experienced ICD battery replacement, and less often had experienced ICD shocks. There were no gender differences in ICD indication or type of ICD implanted.

Mean scores on the psychosocial and cognitive variables are indicated in Table 1. Women had poorer quality-of-life, were more anxious, had lower perceived control, lower levels of social support, and lower ICD knowledge scores than men. There were no gender differences in type-D personality score or depression scores.

When patients were categorized as having type-D personality or symptoms of anxiety or depression using the standardized cut point, there were no differences in the proportion of men (8.2%) or women (8.8%) with depressive symptoms (χ^2 0.166, p = .67) or type-D personality (men 15.9%, women 19.1%, χ^2 3.32, p = .08). There was a higher proportion of women (20.5%) than men (14.7%) with anxiety symptoms (χ^2 11.45, p = .001). There are no standardized cut points for quality-of-life, social support, and perceived control thus similar comparisons were not made for these variables.

Predictors of Symptoms of Anxiety, Depression and Quality-of-Life in Men and Women

Anxiety.

Different sets of predictors were significant for men and women. With regard to anxiety in men, 56% of the variance (p < .001) was explained by the model and of the predictors entered, age, ICD experience, ICD indication, shock experience, comorbidity burden, social support, perceived control, symptoms of depression, type-D personality and ICD knowledge were significant predictors (Table 2.2). Specifically, younger age, worse ICD experience, primary prevention indication, previous shock experience, higher

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comorbidity burden, poor social support, low perceived control, depressive symptoms, type-D personality, and low ICD knowledge scores predicted presence of anxiety in men. The greatest change in R^2 (43%, $p < .001$) occurred with the addition of the block containing the psychosocial variables.

Among women, 55% of the variance ($p < .001$) was explained by the model, and ICD experience, perceived control, symptoms of depression, and type-D personality were the only significant predictors in the model (Table 2.2). Again, the largest amount of variance was explained by the addition of the psychosocial block (46%, $p < .001$). Worse ICD experience, lower perceived control, depressive symptoms, and type-D personality predicted anxiety in women.

Depression.

With regard to symptoms of depression, the model explained 58% of the variance in depression among men ($p < .001$), and the step that increased the variance most was the block containing the psychosocial variables (45%, $p < .001$). Older age, lower education level, longer time since ICD implantation, ICD implanted for secondary prevention, worse ICD experience, higher comorbidity burden, low levels of social support, low perceived control, higher anxiety, and higher type-D personality scores were independently associated with higher depression scores in men (Table 2.3).

Among women, the model explained 54% of the variance in symptoms of depression ($p < .001$), while psychosocial variables contributed the largest R^2 at 46% ($p < .001$). The only significant independent predictors of symptoms of depression among women were higher comorbidity burden, poor social support, symptoms of anxiety, and type-D personality (Table 2.3).

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Quality-of-Life.

Among men, the model explained 39% of the variance in quality-of-life, with 23% of the variance explained by the step containing the psychosocial variables. Type of device, indication for ICD, ICD experience, comorbidity burden, perceived control, anxiety, and symptoms of depression were independent predictors of quality-of-life in men. Specifically, implantation of a CRT-D, implantation for secondary prevention, worse ICD experience, higher comorbidity burden, lower perceived control, higher anxiety, and higher levels of depression were associated with poorer quality-of-life (Table 2.4).

Among women, the model explained 37% of the variance in quality-of-life, with 24% of the variance explained by the psychosocial step. Only ICD experience, comorbidity burden, perceived control, and symptoms of anxiety and depression contributed independently to the model. Worse ICD experience, higher comorbidity burden, greater depression and anxiety symptoms, and higher type-D personality scores were associated with worse quality-of-life (Table 2.4).

Discussion

Most ICD recipients fare well psychologically, but about 20% of patients do not, exhibiting symptoms of anxiety or depression,[12] and in some populations the prevalence may be higher.[35] We demonstrated a higher prevalence of symptoms of anxiety among women compared to men, as well as worse quality-of-life. Depressive symptoms did not differ between the genders. Predictors of the symptoms of anxiety, depression and quality-of-life differed between genders. Psychosocial variables were most often responsible for the majority of variance in the predictive models for both gender groups.

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Previous study results on this topic have been inconsistent,[29] largely due to small sample sizes and the relatively low number of women included in these studies, 9-23%.[59]

Higher levels of symptoms of anxiety were noted in female ICD recipients in this study. This finding is consistent with other studies of psychological distress in ICD recipients.[29, 33] Individuals, particularly women, with a clustering of high ICD concerns and type-D personality traits have been identified in the literature as being at high risk for anxiety.[60] High levels of anxiety in cardiovascular patients have been linked to poor adherence to medications and overall treatment plans.[61, 62] These factors may be pathways by which anxiety can affect outcomes in this patient population. Previous findings regarding anxiety as a predictor for ventricular arrhythmias and subsequent ICD discharges have been mixed.[63-66] A number of researchers have investigated the link between anxiety and cardiovascular disease in general, but few studies have focused on the links between psychological distress and outcomes in ICD recipients. Further large-scale prospective studies are necessary to verify these links in this patient population. In a large cohort of Canadian ICD recipients who were referred to 18 implantation centers and followed for one year, female ICD recipients were at greater risk of complications, both major and minor. These researchers found that women had a 1.6 fold increase of complications over time with lead-related complications occurring most frequently.[67] The experience of lead related complications has previously been shown to be associated with greater psychological distress in women.[68] However, since we did not collect data on complications from medical records, we do not know if this is the case in our sample.

Potential pathways of increased anxiety in female ICD recipients include receipt of shock, fear of death, body image change, and role loss specific anxieties.[29, 69] In men,

younger age and shocks were predictors of anxiety. High levels of anxiety in both men and women may be related to gender roles in society.[70] The threat of sudden cardiac arrest and the ICD may threaten socially normed gender roles. Regardless of the pathway of anxiety in this patient population, when planning interventions healthcare providers should be cognizant of the level of health literacy of individuals. Health literacy is the ability to understand and apply health information to make and communicate decisions regarding healthcare with family members and providers.[71-75] Lower levels of health literacy can impair an individual's understanding of health and wellness. Little is known about the impact of health literacy on the psychological distress of ICD recipients. The role of limited health literacy and misunderstandings related to the function and impact of the ICD on the psychological status of recipients should be further explored.

Levels of depressive symptoms did not vary between the genders. However, the level of depressive symptoms was a significant predictor of both symptoms of anxiety and quality-of-life in men and women in this model. The American Heart Association has issued guidelines for the screening, treatment, and referral for depression in patients with coronary heart disease.[76] There are currently no specific guidelines or recommendations for screening, treatment, and referral for depression in ICD recipients. Given the impact of depression on outcomes in these individuals,[77] it would be prudent to investigate the feasibility and utility of screening for depression in this patient population as well, many of whom have ischemic cardiovascular disease. Individuals who report or screen positive for clinically significant psychological distress should be referred to psychiatric services for further assessment and appropriate therapies.[78] For both gender groups, comorbidity burden, social support, symptoms of anxiety, and type-D personality disorder predicted

depressive symptoms. Additionally for men, older age and lower levels of education, but not ICD knowledge were predictive of depressive symptoms. The cause of this gender difference is not immediately clear. For men, increased age and lower levels of education may indicate difficulty fitting in to the workforce with resulting lower levels of income. Information regarding level of income was not collected in this study.

The majority of the variance in the predictive models for quality-of-life was explained by the addition of the psychosocial variables. Common predictors between men and women included a negative predictive relationship between symptoms of anxiety/depression, and comorbidity burden with quality-of-life. Additionally, CRT-D, secondary prevention, and overall ICD experience were predictive variables for men. Secondary prevention was found to be a predictor of anxiety, depression, and quality of life in men but not in women. The underlying reason behind this gender difference is unclear. Many of the participants in this study

had devices implanted prior to the change in implant guidelines to include indications for primary prevention. This timing may account for the large number of secondary prevention indications in the study participants. There were no differences in the implant indications between men and women.

These results echo other findings in the literature[33, 34, 79] and reiterate the importance of screening, treating, and referring ICD recipients for anxiety and depression, which could potentially improve the quality-of-life and other outcomes for this patient population. Gender differences in the quality-of-life of men and women living with ICDs has seldom been explored.

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Limitations of this study include the cross-sectional design and the use of self-report instruments. Levels of psychological distress may have influenced the response to the request for participation, the very depressed may have lacked the motivation to answer or return the questionnaires, while the very anxious may have been more motivated to return the questionnaires. The method of survey delivery through the mail does have limitations as well. However, due to the fact that the participants represent the entire population of ICD recipients in the country of Sweden, this design was the most plausible for collection of a large amount of data over a large geographical region.[80]

Strengths of the study include the use of a nation-wide sample, high response rate, large sample size, and a large number of female participants. This is in contrast to many of the other studies on the topic that have had small sample sizes and insignificant power for gender comparisons.

Future research should focus on the role of gender itself as a predictor of psychological distress and decreased quality-of-life. These studies should include large numbers of women. The current study focused on symptoms of general anxiety in gender groups, future studies should focus on device related anxieties for women, including: shock, death, body image, and role loss specific anxieties.[29] Large-scale interventions targeting anxiety issues in women before and after ICD implantation should be undertaken. The results of small pilot studies have shown a positive influence of cognitive behavioral therapy (CBT) and support groups on the level of anxiety of female ICD recipients[9, 81] but no large-scale interventions have been instituted to our knowledge. A review of literature published by Pedersen and colleagues[59] in 2007 on this topic, identified two small randomized control trials of CBT in ICD recipients with sample

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sizes of 49 and 70 participants. The results of the studies were mixed with CBT having a positive effect on anxiety levels and exercise capacity. These studies did not indicate any impact on depressive symptoms and quality-of-life. Larger sample sizes and longer follow up time may help to clarify the impact of CBT on symptoms of anxiety and depression, as well as quality-of-life.

A search of the literature indicates that no large-scale intervention trials have taken place since that time. The widespread use of the ICD as a treatment for primary and secondary prevention of sudden cardiac arrest requires a more thorough understanding of the psychological impact on the individuals for whom this life saving technology is necessary.

Conclusion and Clinical Implications

In conclusion, the study showed that women differ from men on several patient reported outcomes. Based on our findings, women may have different needs with regard to psychosocial support compared to men following ICD implantation in clinical practice. The development of gender-specific psychological and educational interventions (preferably using new information technology and taking into account the participants health literacy level) could elucidate whether gender differences as predictors of symptoms of anxiety, depression, and quality-of-life are a true mechanism of disparity or if these differences are due to other factors such as socio-economic status, pre-implantation psychological profile, or post-operative complications.

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Table 2.1: Patient Characteristics for the Total Sample, and Compared by Gender, N = 2771

	All N=2771 Mean ± SD or N (%)	Male n=2200 Mean ± SD or N (%)	Female n=571 Mean ± SD or N (%)	P Value
Age, years	66 ± 12	67 ± 11	61 ± 13	< .001
Time since implant, years	4.7 ± 3.9	4.5 ± 3.7	5.4 ± 4.5	< .001
Living alone, vs with others	557 (20.2)	414 (18.9)	143 (25.2)	.001
Education ≤ 9 years, vs > 9 years	899 (32.7)	759 (34.8)	140 (24.6)	< .001
CRT-D, versus ICD	640 (23.1)	517 (23.5)	123 (21.6)	.34
ICD placed for secondary prevention, vs primary	1782 (64.3)	1411 (64.1)	371 (65.0)	.71
Battery replacement, yes	703 (25.4)	516 (23.5)	187 (32.7)	< .001
Experienced shocks, yes	968 (35.3)	791 (36.3)	177 (31.2)	.02
Total Comorbidities	2.7 ± 1.9	2.81 ± 1.9	2.41 ± 1.8	< .001
Quality of life (mean index) score	.82 ± .21	.83 ± .20	.79 ± .23	< .001
HADS- depression score	2.9 ± 2.9	2.9 ± 2.9	3.1 ± 3.0	.25
HADS- anxiety score	3.8 ± 3.7	3.6 ± 3.6	4.6 ± 3.9	< .001

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Type-D Personality Scale score	13.8 ± 10.0	13.6 ± 9.9	14.4 ± 10.2	.069
Control Attitudes Scale score	19.2 ± 5.1	19.4 ± 5.0	18.4 ± 5.6	< .001
Multidimensional Social Support Scale score	72.4 ± 14.5	72.7 ± 14.1	71.1 ± 16.0	.030
End of Life ICD Questionnaire- Knowledge score	6.7 ± 2.7	6.8 ± 2.7	6.5 ± 2.8	.020

Legend: CRTD = cardiac resynchronization therapy-defibrillator; HADS = Hospital Anxiety and Depression Scale; ICD = implantable cardioverter defibrillator

Table 2.2: Multiple Linear Regression for Prediction of Anxiety in Men and Women

Men	Unstandardized Coefficient β	Standard Error	Standardized Coefficient β	P Value
Age	-.039	.006	-.116	< .001
Household Status	-.188	.149	-.020	.206
Education	.141	.116	.019	.224
Time since implant	-.028	.021	-.029	.193
CRTD	.027	.132	.003	.838
Secondary Prevention	-.319	.122	-.043	.009
Replacement	-.084	.180	-.010	.641
ICD Experience	.392	.102	.060	< .001
Previous Shock Experience	-.168	.073	-.035	.022
Total Comorbidities	.092	.030	.049	.003
Social Support	.010	.004	.037	.032
Control	-.076	.012	-.106	< .001
Depression	.522	.025	.429	< .001
Type-D Personality	.109	.007	.302	< .001
Knowledge	-.054	.021	-.040	.010

Women				
Age	-.015	.011	-.052	.149
Household Status	.356	.286	.039	.214
Education	.551	.284	.061	.053

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Time Since Implant	.035	.041	.040	.401
CRTD	.136	.302	.014	.654
Secondary Prevention	-.377	.272	-.046	.166
Replacement	.406	.394	.048	.303
ICD Experience	.716	.190	.116	< .001
Previous Shock Experience	-.197	.169	-.036	.244
Total Comorbidities	-.059	.074	-.027	.423
Social Support	.010	.008	.040	.247
Control	-.116	.024	-.163	< .001
Depression	.498	.052	.378	< .001
Type-D Personality	.131	.015	.339	< .001
Knowledge	-.068	.046	-.047	.142

Legend: CRTD = cardiac resynchronization therapy-defibrillator; ICD = implantable cardioverter defibrillator

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Table 2.3: Multiple Linear Regression for Prediction of Depression in Men and Women

Men	Unstandardized Coefficient β	Standard Error	Standardized Coefficient β	P Value
Age	.020	.004	.071	< .001
Household Status	.018	.119	.002	.881
Education	-.214	.093	-.034	.022
Time Since Implant	.045	.017	.056	.009
CRTD	.181	.106	.026	.089
Secondary Prevention	.211	.098	.034	.032
Replacement	.244	.145	.035	.092
ICD Experience	.174	.082	.032	.034
Previous Shock Experience	.068	.059	.017	.246
Total Comorbidities	.141	.024	.091	< .001
Social Support	-.022	.004	-.105	< .001
Control	-.067	.010	-.114	< .001
Anxiety	.337	.016	.410	< .001
Type-D Personality	.084	.006	.286	< .001
Knowledge	.007	.017	.007	.660
Women				
Age	-.003	.008	-.014	.712
Household Status	-.271	.221	-.039	.221

Education	-.155	.220	-.022	.482
Time Since Implant	-.019	.032	-.029	.548
CRTD	.019	.233	.003	.936
Secondary Prevention	.036	.210	.006	.866
Replacement	.016	.304	.002	.959
ICD Experience	-.029	.149	-.006	.846
Previous Shock Experience	.027	.131	.007	.834
Total Comorbidities	.278	.056	.166	< .001
Social Support	-.033	.006	-.177	< .001
Control	-.004	.019	-.008	.814
Anxiety	.297	.031	.391	< .001
Type-D Personality	.086	.012	.292	< .001
Knowledge	-.019	.036	-.018	.593

Legend: CRTD = cardiac resynchronization therapy-defibrillator; ICD = implantable cardioverter defibrillator

Table 2.4: Multiple Linear Regression for Prediction of Quality of Life in Men and Women

Men	Unstandardized Coefficient β	Standard Error	Standardized Coefficient β	P Value
Age	.000	.000	-.026	.185
Household Status	-.003	.010	-.006	.739
Education	.006	.008	.014	.442
Time Since Implant	-.001	.001	-.022	.395

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CRTD	-.019	.009	-.040	.030
Secondary Prevention	-.019	.008	-.045	.020
Replacement	-.008	.012	-.017	.492
ICD Experience	-.022	.007	-.058	.002
Previous Shock Experience	.008	.005	.031	.088
Total Comorbidities	-.018	.002	-.172	< .001
Social Support	.000	.000	-.006	.786
Control	.004	.001	.110	< .001
Anxiety	-.015	.001	-.256	< .001
Depression	-.020	.002	-.296	< .001
Type-D Personality	.001	.000	.049	.043
Knowledge	.001	.001	.009	.627

Women

Age	.000	.001	-.016	.710
Household Status	.012	.019	.023	.541
Education	-.006	.019	-.011	.762
Time Since Implant	-.005	.003	-.108	.056
CRTD	.013	.020	.025	.515
Secondary Prevention	.027	.018	.057	.144
Replacement	-.020	.027	-.041	.462
ICD Experience	-.041	.013	-.116	.002
Previous Shock Experience	-.017	.011	-.054	.142

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Total Comorbidities	-.027	.005	-.212	< .001
Social Support	.000	.001	-.035	.390
Control	.002	.002	.043	.286
Anxiety	-.012	.003	-.202	< .001
Depression	-.031	.004	-.411	< .001
Type-D Personality	.001	.001	.068	.172
Knowledge	-.004	.003	-.053	.169

Legend: CRTD = cardiac resynchronization therapy-defibrillator; ICD = implantable cardioverter defibrillator

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Multi-morbidity Burden and Quality of Life in Implantable Cardioverter

Defibrillator Recipients: Results from a Nationwide Study

Introduction

Implantable cardioverter defibrillators (ICDs) are the first line therapy for individuals at higher risk for or with a prior history of ventricular arrhythmias. [1-3] The ICD is utilized for both primary and secondary prevention of sudden cardiac arrest, particularly in the context of heart failure.[4-6] According to the most recent global survey by the World Society of Arrhythmias, 222,407 new ICDs were implanted and 105,620 devices were replaced in 2009, the most recent year for which international data is available.[7] The prevalence of multi-morbidity in the ICD population is approximately 25%.[8] Multi-morbidity is associated with poor health outcomes in this population.[9, 10] This association between illness burden and poor health outcomes may affect ICD recipients' quality-of-life (QOL) and psychological responses to having an implanted device.[8, 11, 12]

Multi-morbidity is defined in the literature as two or more significant medical conditions unrelated to the index condition.[13, 14] Although multi-morbidity is defined by the existence of a number of chronic disease processes, it is not merely the sum of these diseases. Different conditions have varying levels of associated burden, but the negative effects of chronic illness are compounded by the addition of further comorbidities, increasing the level of disability and healthcare utilization.[15] The prevalence of multi-morbidity in ICD recipients has not been well studied. Reports of the prevalence of multi-

morbidity in the general population have varied from 13-80% based upon the definition of multi-morbidity used by the researchers.[13, 14]

The links between individual chronic illnesses, QOL, and psychological response have been well studied, particularly in cardiovascular disease. However, models may not be generalizable to ICD recipients due to the complexity of implant indications and the existence of multiple comorbidities. ICD implantation occurs in individuals with multi-morbidities, yet little is known about the prevalence of multi-morbidity in ICD recipients and the often-complex interactions between ICDs and other chronic diseases on the psychological responses of this population. Therefore, the overall aim of this study was to determine the prevalence of anxiety and depressive symptoms, Type-D personality, and ICD-related concerns (e.g. worries about battery depletion or limitations due to therapy) in ICD recipients with varying levels of comorbidities, and to examine the association between multi-morbidity burden and QOL while controlling for sociodemographic, clinical, ICD-related, and psychosocial variables.

Methods

Study design, sample, and data collection

All adults listed in the Swedish ICD and Pacemaker Registry in 2012 who had an ICD with or without cardiac resynchronization therapy (CRT-D) implanted for at least one year were invited to participate in this study.[16-19] There were no further inclusion or exclusion criteria except willingness to participate and return the informed consent document. The Swedish ICD and Pacemaker Registry is a national database, in which patients with a cardiac implantable electronic device (CIED) have been followed since

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1989. Between September and October of 2012, all 5,535 eligible individuals with an ICD or CRT-D were mailed a survey with a self-addressed stamped envelope for its return. One reminder was mailed three to four weeks following initial contact. No further attempts were made to obtain return of the survey after the reminder. This cross sectional study received ethical approval from the Regional Ethics Committee for Human Research at the University of Linkoping, Sweden.

Measures

Multi-morbidity burden

Researchers had no access to patients' medical records, therefore information on comorbidities were obtained via a self-report questionnaire. Multi-morbidity has often been measured by a simple count of multi-morbid conditions or a weighted count that consider the severity of each condition in the overall burden score,[20] the latter was the case in our study. Our questionnaire listed 14 significant, common comorbidities (e.g. heart failure, diabetes, and cancer) for which participants indicated the presence of and discomfort related to each condition (e.g. no-0; yes, but no discomfort-1; yes, slight discomfort-2; or yes, much discomfort-3). Participants also had the option of adding one other unlisted comorbidity for a total of 15. The multi-morbidity burden was scored by the total number of comorbidities times the state of discomfort. The range of multi-morbidity burden was 0 to 45, with higher numbers indicating higher levels of burden. The use of self-reported and self-rated multi-morbidity burden has been used successfully in multiple studies and populations.[21-27]

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Anxiety and Depressive Symptoms

The Hospital Anxiety and Depression Scale (HADS) is a 14-item instrument that includes two subscales that measure anxiety and depression (7 items each). Scores on each subscale range from 0 to 21 where higher scores reflect higher levels of anxiety or depressive symptoms. The reliability and validity of the HADS has been demonstrated in multiple populations. In accordance with current practice, a cut off value of >8 for each construct has been identified for use in categorizing patients as having symptoms of anxiety or depression.[28] The Cronbach's alpha for this scale in our study was .859.

Quality of Life

Quality-of-life was measured using the EuroQol-5D (EQ-5D) mean index score,[29] a standardized instrument for the measurement of health-related QOL, which is based on the five domains of mobility, self-care, pain/discomfort, and anxiety/depression.[30] Participants' response to items is based on whether the item is associated with no problems, some problems, or severe problems. The maximum score is one with higher scores indicating a better QOL. The EQ-5D has been used extensively in cardiovascular research and has been shown to have good validity and reliability. [30-33]

Type-D Personality

The type-D personality, a distressed personality type, consists of two relatively stable traits: negative affectivity, and social inhibition. The instrument includes seven items that assess negative affectivity (e.g., "I often feel unhappy") and seven items that assess social inhibition (e.g., "I am a closed kind of person") (ref). The 14-item Type-D scale (DS14) was developed among a cardiac population and has well-established

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reliability and validity. Scores from both subscales are summed and a standardized cut-point $\geq$10 identifies a Type-D personality.[34] The Cronbach's alpha for this scale in our study was .971.

ICD-Related Concerns

ICD-related concerns were assessed using the Implantable Cardioverter Defibrillator Concerns Questionnaire (ICDC). In this study, we used the shortened form of the original 20-item questionnaire, the ICDC-8.[35-37] This instrument measures the number and severity of patient concerns related to the ICD on a five item Likert scale. The items are scored 0 (I am not worried at all) to 4 (I am very much worried) with up to a total number of eight concerns and a maximum severity score of 32. The items are directed at perceived limitations related to the presence of the ICD (e.g. exercising too hard and causing my device to fire) and device specific concerns (e.g. ICD battery depletion). The ICDC has been found to be valid and reliable in multiple populations.[35, 37] The Cronbach's alpha for this scale in our study was .968.

ICD Knowledge, Experience, and Sociodemographics

Knowledge of the ICD was measured using the 11 item knowledge subscale of the Experiences, Attitudes and Knowledge of End-of-Life issues in Implantable Cardioverter Defibrillator Recipients Questionnaire (EOL-ICD).[18] True/false answers are chosen by the respondent to statements (e.g. to turn off the ICD shocks is the same as active euthanasia; an ICD always delivers shocks at the end of life). The correct answers are summed for a total value of 0-11, with higher scores indicating a higher level of ICD knowledge. The ICD experience was measured using the experience subscale of the

EOL-ICD. Participants were asked to rate their experience with the ICD on a Likert type scale from 1 (very good) to 4 (very bad). Information on clinical variables, including indication for ICD implantation, cardiac resynchronization therapy, generator replacement, and time since implantation were obtained from the Swedish ICD and Pacemaker registry. Other items in this portion of the instrument include have you received one or more shocks from your ICD. The EOL-ICD includes sociodemographic questions related to age, gender, ethnicity, marital and occupational status, as well as education level. The EOL-ICD questionnaire has been demonstrated to be valid and reliable in the ICD recipient population.[18]

Statistical analyses

All statistical analyses were completed using SPSS version 22 (IBM Corp., Armonk, NY, USA). Characteristics were compared between categories of multi-morbidity based on quartile measurements in the sample ($\leq$ 16; 17-19; 20-22; and $\geq$ 23) using X^2 and ANOVA with post-hoc Bonferroni adjustment. The prevalence of anxiety and depressive symptoms, Type-D personality, and 1ICD-related concerns were compared between the four comorbidity burden groups.

We originally attempted multiple linear regression, but the assumption of existence of a linear relationship between the predictor variables (collectively and individually) and the dependent variable was violated and it was impossible to transform the dependent variable sufficiently. Thus, we used logistic regression to determine predictors of QOL, as quantified using the EQ-5D mean index, categorized dichotomously using the 50th percentile of the group as a cut-point. Predictors used were

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sociodemographic (age, gender, education level, relationship, and work status), clinical (duration of implant, device indication, history of shock, CRT-D, device replacement), ICD-related factors (ICD knowledge, ICD experience, and ICD concerns), psychosocial (depressive symptoms, anxiety symptoms, and Type-D personality), and finally multi-morbidity burden score. These grouped predictors were entered in steps to determine the relative contribution of each category to the variance in QOL. These steps were repeated for each category of multi-morbidity burden for comparison between groups and the overall sample.

The assumptions of (1) linear relationship between the continuous level independent variables and the logit transformation of the dependent variable, (2) no multicollinearity, and (3) no significant outliers or influential points were tested. There were no violations.

Results

Background characteristics

Of the 5,535 ICD recipients invited to participate, 3,067 responded for a 55% response rate for all ICD recipients in Sweden. Of these, 2,658 had data on the variables used in this analysis (Table 1). There was no way to determine the number of invited individuals who died between the time of implant and the time of data collection. The mean age of the respondents was 65 ± 12 years with a range of 19-94 years of whom 20.6% were female. Time since implantation ranged from one to 23 years with a mean of 4.7 ± 3.9 years: 22.7% had a CRT-D device, 35.4% had a device implanted for primary prevention of cardiac arrest, and 25.6% had previously undergone generator replacement.

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Comparison of Sociodemographic, Clinical and Psychosocial Characteristics Based on Multi-morbidity Burden

Those individuals with highest multi-morbidity burden (i.e., quartile 4; Table 3.1) tended to be older (68 $\pm$ 9 years), male (80.2%), less educated (37.6%), lived alone (25.8%), and were less often employed outside of the home (6.4%). Clinically, this group had their device implanted for a shorter time (4.4 $\pm$ 3.9), more often for primary prevention (44.5%), and more had CRT-D devices implanted (34.4%). Stark differences were found in the psychosocial variables. For those individuals with the highest level of multi-morbidity burden, the prevalence of depression (19.3%), anxiety (29.0%), and Type D-personality disorder (24.5%) were significantly higher than the other burden groups. Individuals with higher levels of multi-morbidity burden also had lower levels of ICD knowledge (6.3 $\pm$ 2.8) and higher ICD concerns (9.6 $\pm$ 8.2) and reported a lower QOL (.68 $\pm$ .21).

Logistic regression analysis was conducted to predict QOL in ICD recipients (Table 3.2). The overall model was significant (P <.001) with Hosmer and Lemeshow test results demonstrating good fit of the data to the model (*P*= .355). The model correctly classified 72.7% of the cases overall. Multi-morbidity burden was a significant predictor of worse QOL, with every one unit increase in multi-morbidity burden increasing the odds of worse QOL by 1.3 times. Hierarchical logistic regression was used to assess the predictability of multi-morbidity burden for QOL in ICD recipients controlling for the influence of sociodemographic, clinical, ICD-related factors, and psychosocial variables.

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Other significant predictors of worse QOL included female sex, not working outside the home, history of shock, worse ICD experience, higher ICD Concerns, the presence of anxiety, depression, or Type D personality disorder. Women were 1.6 times more likely to report worse QOL than men. ICD recipients not working were 1.5 times more likely to report worse QOL than those reporting employment outside the home. Those individuals with a history of a shock were 1.3 times more likely to report worse QOL than those who had never received defibrillation therapy from the device. For every one unit increase in ICD experiences (i.e., more negative experiences) and concerns (i.e., greater concerns) the odds of worse QOL were increased by 1.6 and 1.01 times respectively. The presence of anxiety increased the odds of worse QOL by 7.8 times, depression by 2.4 times, and Type D personality disorder by 1.7 times.

Predictors of worse QOL in individuals with the lowest levels of multi-morbidity burden ($\leq$ 16) included female sex, higher ICD concerns, and the presence of anxiety or Type D personality disorder (Table 3.3). Interestingly, for this group, multi-morbidity burden was not predictive of QOL. Predictors of worse QOL in individuals in quartile 2 (17-19) included no employment outside the home, a history of shock, higher ICD concerns, the presence of anxiety and multi-morbidity burden (Table 3.4). This group was the only one for which no employment outside the home or a history of shock was a significant predictor of worse QOL. Predictors of worse QOL were the same for quartiles 3 (20-22) and 4 ($\geq$23). These were worse ICD experience, the presence of anxiety, and multi-morbidity burden (Tables 3.5 & 3.6).

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Discussion

Psychological distress

Multi-morbidity and the presence of psychological distress (anxiety, depression, and/or Type-D personality disorder) are associated with poor outcomes in the ICD population.[8-10] While the majority of ICD recipients respond well psychologically to device therapy, approximately 10-20% will exhibit symptoms of distress.[38, 39] We found a markedly higher prevalence of anxiety and depressive symptoms, as well as Type-D personality disorder in those ICD recipients with the highest levels of multi-morbidity burden ($\geq$ 23).

Within the general population, the prevalence of depression and generalized anxiety is 3.0[40] and 3.1% respectively.[41] In a systematic review of 45 studies of ICD recipients, Magyar-Russell et al.[38] reported that the prevalence of psychological distress was higher in the ICD population with depression rates at 11-18% and generalized anxiety rates at 15-19%, similar to levels of distress in other cardiovascular disease populations. Our results indicated similar levels of distress in our overall population with higher levels in the group with the greatest multi-morbidity burden who had a 19.1% prevalence of depression and 28.4% prevalence of generalized anxiety.

Fear of shock, death, device malfunction, body image concerns, and loss of social role have all been noted as explanations for increased anxiety and depression in this population[42, 43] In a study of 213 ICD recipients, Morken et al. found that the perceived support of healthcare professionals helped to allay the fear and buffer the psychological distress related to ICD and improved overall acceptance of the device.[43] Further studies

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should focus on the specific concerns of ICD recipients and interventions to support acceptance of the device and its impact on recipients to minimize distress.

Quality of Life

Our results indicate that greater multi-morbidity burden is a predictor of lower QOL, which echoes the findings of studies in the general population.[14, 44, 45] Multi-morbidity affects multiple dimensions of QOL (e.g. physical, psychological, and social). The fact that higher levels of multi-morbidity burden affect QOL is a common sense conclusion supported with scientific literature. A systematic review of studies for which QOL was the main outcome measure included seven international studies that indicated the negative impact of multi-morbidity on QOL.[14] All of the reported studies noted this relationship, particularly for the physical component of QOL and two studies indicated that a high multi-morbidity burden reduced the known relationship between age and lower QOL.[14, 44]

The ability to care for one's self is a significant component of QOL.[29, 30, 46] Multi-morbidity can make self-care more difficult as multiple disease processes must be managed by an individual, often with conflicting medical advice. Dietary restrictions and medication management are two areas in particular that can cause difficulties in this domain.[47-49] Limitations in mobility and living with chronic pain can impact QOL and lead to significant levels of anxiety and/or depression, impacting the physical, psychological, and social domains of QOL.[49] Stewart et al. recommend a multi-disciplinary framework for optimizing health outcomes in individuals with heart failure and multi-morbidity, a significant portion of whom would be ICD recipients.[50] Following

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these steps during the time that ICD implantation is being considered and throughout ICD treatment may improve outcomes and ultimately QOL in ICD recipients.

This recommended framework includes five key steps to improve clinical outcomes in individuals with heart failure (and is here adapted to the ICD recipient), using the acronym *ARISE*.[51] 1) *A*cknowledge the association of multi-morbidity with poor outcomes and a significant impact on QOL, 2) *R*outinely assess multi-morbidity during all phases of the ICD implant and treatment trajectory, 3) *I*dentify individual priorities and goals while considering multi-morbidity burden and the initiation or continuation of appropriate device therapy, 4) *S*upport individualized multi-disciplinary management and care of ICD recipients, and 5) *E*valuate physical and psychological health, as well as QOL outcomes on a continuing basis.[51] It would be prudent to conduct future research using this multi-disciplinary approach to the management of ICD recipients to determine the impact of this intervention on health and QOL outcomes.

Our study adds to the literature as we studied a large national cohort of ICD recipients rather than a smaller selected sample. Additionally our use of a measure of multi-morbidity burden rather than merely the number of comorbidities provides a better understanding of the severity and cumulative impact of multi-morbid conditions on the QOL in ICD recipients.

Other predictors of QOL in ICD recipients included: female sex, not working outside the home, history of shock, negative ICD experience, higher levels of ICD concerns, and the presence of anxiety, depression, or Type-D personality disorder. The impact of ICD shock on QOL is convoluted and as such studies regarding this topic have

been difficult to untangle.[52-57] While ICD recipients often report the fear of shock as a source of anxiety, device therapy is also considered a lifesaver, which helps to allay fears of death and provides a strong feeling of safety in some patients [5, 58, 59] Study results have been mixed regarding the relationship between shocks and psychological well-being or QOL.[52-55] Our results based on a large national sample indicate that there is a relationship between shocks and lower QOL, however the relationship between QOL and ICD concerns overall was a stronger predictor. Interventions to fully educate and prepare recipients for potential device shocks (a shock plan) and facilitate adjustment to life with an ICD may help to lessen the impact of these predictors.[60-62]

We found female sex to be a predictor of lower QOL in ICD recipients. Multiple studies, including a previous analysis of the data used in this study, found similar results.[63-65] Women often reported higher levels of anxiety due in part to body image changes and gender role issues, in addition to the same variables reported by men.[39, 65] Future studies should determine variables that are important to both men and women and lead to interventions that include discussions of the impact of the device on perceived gender roles.

Our results indicated that those not working outside the home were more likely to report lower QOL. ICD recipients may not be able to continue in their chosen employment due to the device or underlying arrhythmic or cardiovascular condition.[44] The loss of a job or unstable financial situations can negatively affect QOL.[66] This is particularly pronounced in individuals who are the breadwinners for their family or single.[67]

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Little is known about the perceived experience of ICD recipients.[58] A search of the literature results in little information regarding this topic. As is the case for self-reported health status, asking patients about the quality of the overall experience with the ICD may alert the provider to potential problems with adjustment to the device. Further research in this area is needed as this simple one question assessment may indicate a need for intervention.

ICD concerns encompass the domains of perceived limitations due to the device and worries related specifically to device function. Misperceptions related to device function may lead to unnecessary worry and self-imposed limitations that may lead to worse QOL.[35] It is important to evaluate the recipients' knowledge of the device and clear up any misperceptions regarding their ability to function physically, psychologically, and socially. Educational interventions should take the health literacy level of participants into account in order to provide a complete understanding and informed decision making on the part of the ICD recipient.[68]

Psychological distress negatively impacts the QOL in ICD recipients.[42, 69] Anxiety, depression, and/or Type D personality disorder may increase the level of perceived limitations in the ICD recipient population.[70] [71] Cognitive behavioral therapy and other psychological interventions may be of use in this patient population.[72] As distress decreases so may perceived limitations which could possibly increase QOL.

Limitations of this study include the cross-sectional design and self-reported comorbidities. Patients may not report all existing diagnoses or may be unfamiliar with medical terminology of their disease processes. A chart review or clinical interview

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would be helpful to ensure that all the known information was captured. However, this collection was done via a mailed survey with no access to medical records for the national sample. Mailed surveys present limitations of their own but we employed the recommendations of Dillman [73] to provide the strongest level of science possible with this method.[74] The greatest strength of this study is the fact that it was based on the full population of ICD recipients in Sweden, rather than a representative sample. A reasonable response rate, large sample size, and a large number of female participants in this study also contributed strength to the results.

Clinical implications include the importance of frank discussions regarding the impact of device therapy in individuals with higher levels of multi-morbidity burden prior to implant as well as discussions regarding healthcare choices regarding defibrillation therapy withdrawal and generator replacement particularly in the setting of terminal or severe multi-morbid illnesses as indicated in the current treatment guidelines,[3] which from the perspective of the ICD recipient do not often occur.[17, 75] Educational and psychological interventions pre and post ICD implantation may be of significant benefit in this population.[76]

The ICD is a lifesaving/extending device, yet there are important psychological ramifications with a significant impact on overall QOL and clinical outcomes that should be discussed and considered prior to device implantation, particularly in recipients with multi-morbid conditions. The presence of psychological distress should be monitored and treated in these patients during all phases of device therapy. There is currently an opportunity for improvement in the recognition and treatment of psychological distress in ICD recipients.[77] In order to provide the most appropriate care and to safeguard the

overall health of this population, monitoring for and treatment of psychological distress is needed, particularly for those individuals with a high multi-morbidity burden for whom the distress is more likely. As individuals live longer due to advances in science and medicine, the issues related to multi-morbidity and co-treatment of multiple disease processes are a high priority for research.

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	All N= 2658	Multi-morbidity Burden Score Quartile 1 ≤ 16 n= 502	Multi-morbidity Burden Score Quartile 2 17-19 n= 1019	Multi-morbidity Burden Score Quartile 3 20-22 n= 602	Multi-morbidity Burden Score Quartile 4 ≥ 23 n= 535	P Value
Age in Years (19-94)	65.4 ± 11.6	60.4 ± 14.0	64.9 ± 11.7	67.7 ± 9.6	68.4 ± 8.9	<.001[a]
Female	547 (20.6)	120 (23.9)	217 (21.3)	104 (17.3)	106 (19.8)	.048
Education $\leq$ 9 years	845 (31.8)	127 (25.3)	302 (29.6)	215 (35.7)	201 (37.6)	<.001
Lives Alone	555 (20.9)	94 (18.7)	188 (18.4)	135 (22.4)	138 (25.8)	.003
Works Outside the Home	638 (24.0)	215 (42.8)	300 (29.4)	89 (14.8)	34 (6.4)	<.001
Duration of Implant in Years (1-23)	4.7 ± 3.9	5.2 ± 3.9	4.7 ± 4.0	4.5 ± 3.8	4.4 ± 3.9	.009[b]
Primary Indication	942 (35.4)	109 (21.7)	362 (35.5)	233 (38.7)	238 (44.5)	< .001
History of Shock	940 (35.4)	165 (32.9)	352 (34.5)	215 (35.7)	208 (38.9)	.204
CRT-D	604 (22.7)	51 (10.2)	207 (20.3)	162 (26.9)	184 (34.4)	<.001

Table 3.1. Characteristics by Multi-Morbidity Burden

Device Replacement	681 (25.6)	143 (28.5)	253 (24.8)	153 (25.4)	132 (24.7)	.429
ICD Knowledge (0-11)	6.7 ± 2.7	7.1 ± 2.6	6.8 ± 2.7	6.5 ± 2.7	6.3 ± 2.8	<.001[c]
ICD Experience (1-4)	1.3 ± .56	1.23 ± .51	1.31 ± .58	1.33 ± .57	1.32 ± .56	.013[d]
ICD-Related Concerns (0-32)	8.3 ± 7.7	7.5 ± 7.4	7.9 ± 7.4	8.3 ± 7.6	9.6 ± 8.2	<.001[e]
Depressive Symptoms	227 (8.5)	13 (2.6)	58 (5.7)	53 (8.8)	103 (19.3)	<.001
Anxiety Symptoms	422 (15.9)	39 (7.8)	125 (12.3)	103 (17.1)	155 (29.0)	<.001
Type D Personality	442 (16.6)	52 (10.4)	152 (14.9)	107 (17.8)	131 (24.5)	<.001
Quality of Life (-.349 – 1.000)	.823 ± .208	.936 ± .123	.870 ± .178	.777 ± .193	.679 ± .243	<.001[f]

Reported using n (%) or mean ± SD

[a] All pairwise comparisons significant (p <.001, Bonferroni adjustment) with the exception of quartile 3 vs quartile 4

[b] Pairwise comparisons between quartile 1 vs. quartiles 3 and 4 significant (p <.001, Bonferroni adjustment)

[c] Pairwise comparisons for quartile 1 vs. quartiles 3 and 4 significant (p <.001, Bonferroni adjustment)

[d] All pairwise comparisons significant (p <.001, Bonferroni adjustment)

[e] All pairwise comparisons between quartile 4 and all other quartiles significant (p <.001, Bonferroni adjustment)

[f] All pairwise comparisons significant (p <.001, Bonferroni adjustment)

Table 3.2. Logistic Regression Identifying Predictors of QOL in ICD Recipients.				
Predictor	**B (S.E)**	**Adjusted Odds Ratio**	**95% Confidence Interval**	***P* Value**
Age	-.004 (.006)	.996	.985-1.007	.489
Sex	454 (.120)	1.575	1.244-1.994	<.001
Education	.015 (.105)	1.015	.826-1.246	.889
Employment	.413 (.142)	1.511	1.144-1.994	.004
Time Since Implant	.021 (.019)	1.021	.985-1.059	.253
Implant Indication	-.196 (.108)	.822	.665-1.015	.069
History of Shock	.272 (.107)	1.313	1.064-1.620	.011
CRT-D	.120 (.118)	1.127	.895-1.421	.310
Device Replacement	-.076 (.159)	.926	.679-1.264	.630
ICD Knowledge	.009 (.019)	1.009	.973-1.047	.622
ICD Experience	.483 (.095)	1.621	1.345-1.954	<.001
ICD-Related Concerns	.027 (.007)	1.027	1.012-1.042	<.001
Depressive Symptoms	.881 (.293)	2.412	1.359-4.281	.003

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Anxiety Symptoms	2.058 (.227)	7.833	5.020-12.222	<.001
Type D Personality	.537 (.151)	1.712	1.273-2.302	<.001
Multi-Morbidity Burden	.239 (.017)	1.271	1.230-1.313	<.001

The overall model was significant *(p < .001)* with Hosmer and Lemeshow test results demonstrating good fit of the data to the model *(p .355)* The model correctly classified 72.7% of the cases overall.

Table 3.3. Logistic Regression Identifying Predictors of QOL in ICD Recipients-Multi-Morbidity Burden quartile 1				
Predictor	**B (S.E)**	**Adjusted Odds Ratio**	**95% Confidence Interval**	*P* **Value**
Sex	1.136 (.278)	3.115	1.806-5.372	<.001
ICD-Related Concerns	.053(.018)	1.054	1.017-1.093	.004
Anxiety Symptoms	2.494 (.556)	12.112	4.071-36.039	<.001
Type D Personality	.776 (.388)	2.172	1.016-4.643	.045

The quartile 1 model was significant *(p < .001)* with Hosmer and Lemeshow test results demonstrating good fit of the data to the model *(p .802)* The model correctly classified 80.8% of the cases overall.

Table 3.4. Logistic Regression Identifying Predictors of QOL in ICD Recipients-Multi-Morbidity Burden Quartile 2				
Predictor	**B (S.E)**	**Adjusted Odds Ratio**	**95% Confidence Interval**	***P* Value**
Employment	.439 (.204)	1.552	1.041-2.313	.031
History of Shock	.417 (.163)	1.517	1.103-2.087	.010
ICD-Related Concerns	.038(.011)	1.038	1.016-1.062	.001
Anxiety Symptoms	2.101(.353)	8.172	4.089-16.335	<.001
Multi-Morbidity Burden	.258 (.086)	1.294	1.093-1.531	.003
The quartile 2 model was significant *(p < .001)* with Hosmer and Lemeshow test results demonstrating good fit of the data to the model *(p .523)* The model correctly classified 69.1% of the cases overall.				

Table 3.5. Logistic Regression Identifying Predictors of QOL in ICD Recipients-Multi-Morbidity Burden Quartile 3				
Predictor	**B (S.E)**	**Adjusted Odds Ratio**	**95% Confidence Interval**	*P* **Value**
ICD Experience	.745 (.222)	2.107	1.364-3.255	.001
Anxiety Symptoms	2.003 (.495)	7.413	2.807-19.576	<.001
	.327 (.122)	1.386	1.091-1.762	.008
The quartile 3 model was significant (p <.001)with Hosmer and Lemeshow test results demonstrating a good fit of the data to the model (p, .474) The model correctly classified 70.1% of the cases overall..				

Table 3.6. Logistic Regression Identifying Predictors of QOL in ICD Recipients-Multi-Morbidity Burden Quartile 4				
Predictor	**B (S.E)**	**Adjusted Odds Ratio**	**95% Confidence Interval**	*P* **Value**
ICD Experience	1.646 (.444)	5.186	2.171-12.389	<.001
Anxiety Symptoms	1.628 (.517)	5.092	1.848-14.026	.002
Multi-Morbidity Burden	.181 (.052)	1.198	1.081-1.328	.001
The quartile 4 model was significant (p, <.001) with Hosmer and Lemeshow test results demonstrating good fit of the data to the model (p, .427). the model correctly classified 80.7% of the cases overall.				

Chapter Four

Health Literacy Predicts Cardiovascular Disease in the Male Prison

Population

Introduction

Cardiovascular disease (CVD) is the leading cause of death in prison inmates in the United States.[1] Additionally, former inmates have an increased risk of dying due to CVD events following release from prison compared to the general population.[2] This risk is highest within the first few weeks of release.[2] Many inmates will return to the general public following sentence completion. A significant number of these individuals will be uninsured and lack access to healthcare, resulting in an increase in both the economic and disease burden of CVD.[3] Well known modifiable risk factors associated with CVD risk among prisoners include poor diet, lack of exercise, drug and tobacco use.[4] Another modifiable risk factor that is potentially important in CVD risk is health literacy.[5]

Health literacy is the ability to obtain, process, understand, and apply information in order to make appropriate choices regarding self-care and treatment.[6] Health literacy is composed of multiple domains including print literacy, numeracy skills, information literacy, and oral literacy which are used to synthesize and apply information related to health care decisions.[7] Health literacy is a critical juncture between health education and decision-making. Without adequate levels of health literacy individuals cannot fully engage in self-care or make appropriate decisions about their health and well-being.[8-10]

Health literacy levels are a significant predictor of health status and inadequate levels have been linked to increased CVD risk.[5] Inadequate health literacy is often, but not always associated with lower educational levels and is frequently seen in situations

where health disparities exist.[11-16] Inadequate health literacy may affect CVD risk due to decreased ability to understand and follow directions related to medications, treatments, and lifestyle changes, which may lead to non-adherence to prescribed treatments and an increase in risky behaviors.[13, 17-19] Inadequate health literacy is associated with decreased knowledge of disease and self-care management skills.[16, 20-24]

The education level of prison inmates is lower than the general population, with an estimated 68% of state prison inmates who did not complete high school or the graduate equivalency examination (GED).[25] Given the association of lower levels of education with inadequate health literacy[11, 26] it is likely that health literacy levels among prison inmates are low. Little is known about the association between health literacy levels and risk for CVD events in prison inmates. Accordingly, the purpose of this study was to determine whether health literacy levels independently predict cardiovascular risk in the male prison population.

Methods

Design

This study was conducted using a cross-sectional correlational design. A total of 378 male inmates incarcerated in 4 Kentucky state prisons were enrolled in a behavioral CVD risk reduction intervention. As part of the baseline assessment the male inmates completed a health literacy assessment. The current study includes baseline data from 354 inmates with full data on the variables of interest. Sociodemographic and clinical data were compared between those who did and did not have full data on all relevant variables. There were no differences noted

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between the 354 participants included and the 24 who were excluded from the analysis due to missing data on one or more items.

Sample and Setting

This study was approved by the Institutional Review Board of the University of Kentucky, by the Kentucky Department of Corrections, and by each prison warden from enrolling prisons. Each inmate gave informed consent and signed the consent form. Inmates enrolled met the following criteria: age 18 years or older; currently incarcerated in 1 of 4 medium security Kentucky state prisons with a parole date set for nine months or more beyond study enrollment date; and able to read and write English. Inmates were excluded if they were acutely febrile at time of initial assessment; had a history of an acute cardiac event or cardiovascular intervention; had uncontrolled hypertension; had asthma, chronic obstructive pulmonary disease, cystic fibrosis, insulin dependent diabetes mellitus or chronic heart failure; had been admitted to the psychiatric unit or placed in segregation during the month prior to enrollment date. We were unable to enroll female prisoners at the time because they were housed in a maximum security prison, to which we had no access.

Protocol

The study was advertised at each prison using flyers, word-of-mouth, and recruitment announcements on prison radio or television. All enrollment, consent, data collection and intervention procedures were performed by our trained research staff in the prisons. Inmates completed questionnaires with the assistance of research staff and all clinical measures were done by research staff.

Measures

Health Literacy

Health literacy was measured in this study using an instrument called the Newest Vital Sign (NVS). The NVS is a 6-item questionnaire used to assess the ability to read and apply information from a nutrition label that can be completed in 3-5 minutes.[27] The NVS evaluates both reading and numeracy skills. Scores can range from 0 to 6 and represent the number of questions answered correctly, with higher scores indicating higher levels of health literacy. Individuals who score 4 or more correct answers are unlikely to have inadequate health literacy.[27] Participants were categorized into adequate and inadequate health literacy groups based upon the NVS scoring algorithm with the cut-point of 3 or below indicating inadequate health literacy. Prior psychometric testing of the NVS indicated adequate reliability and validity.[27] The Cronbach alpha for this instrument in our study was 0.76.

Cardiovascular Disease Risk

The Framingham Risk Score (FRS) is an instrument used for prediction of 10 year risk of a CVD event (myocardial infarction or death). The FRS was developed based on the Framingham Heart Study, a prospective cohort study which began in 1948 and is currently in the third generation of participants.[28] The FRS has been revised multiple times as more information was gained from the Framingham study. The FRS is a reliable and valid measure of individual CVD event risk in multiple populations.[29-32] The FRS is determined based on age, gender, total cholesterol, high density lipoprotein (HDL) levels, systolic blood pressure, treatment for hypertension, and smoking status. Scores range from 1 to 30 with higher scores indicating increased 10-year risk for CVD event.

Clinical and Sociodemographic Indicators

Body mass index (BMI) has been used routinely in clinical and research settings to identify individuals and populations at risk for CVD from overweight and obesity.[4] There has been some debate about whether BMI is the most CVD specific of the measures of adiposity. A review of the literature supported the assertion that there was no significant difference between BMI and measures of central obesity in terms of CVD risk prediction.[33, 34] BMI measurement of obesity was chosen for this model, as it is a simple and consistent measurement of obesity.

Multi-morbidity is defined in the literature as two or more significant medical conditions unrelated to the index condition.[35, 36] Multi-morbidity burden was measured by a simple count of self-reported health conditions from a list of ten common health conditions for prisoners including heart disease, diabetes, HIV/AIDS, and previous substance abuse. The simple count method of multi-morbidity burden has been found to be valid and reliable in a number of studies.[37, 38] Education level, ethnicity, marital status, length of sentence, and type of crime committed were obtained from a structured self-report demographic questionnaire and a review of public records.

Data Analysis

All analyses were completed using SPSS (version 22) for Windows. Frequencies and proportions were used to describe the sample in terms of sociodemographic, clinical, and criminal sentence specific information. To compare characteristics between participants with inadequate and adequate health literacy levels, we used the chi square test, and the two tailed student's t-test. The sample was divided into two groups based on published recommended cut off scores to represent inadequate (0-3) and adequate (4-6)

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health literacy levels. Non-linear regression with a gamma distribution was used to determine whether health literacy predicted risk of CVD while controlling for education level, ethnicity, marital status, BMI, and multi-morbidity burden. Age, gender, total cholesterol, HDL levels, systolic blood pressure, treatment for hypertension, and smoking status were not included in the predictive model due to their presence in the FRS equation.

Results

All of the participants were male with a mean age of 36 years and a mean education level of 12 years (Table 4.1). The majority of the participants (85.6%) were not married or partnered and were Caucasian (62.4%), while 35% were African-American. Approximately half (48.4%) were serving sentences of 10-20 years and 8.5% were incarcerated for violent crimes. Mean scores of the FRS were 7.3 $\pm$ 6.9 and ranged from 0 to 30, with a median of 4.7 (25th percentile 2.8, and 75th percentile 9.4). This risk estimate is higher than the observed ten year CVD mortality rate of 4.0 in US males between the ages of 30-39.[39]

Of the 354 inmates (Table 4.1), 27% were categorized in the inadequate health literacy group. In bivariate analyses, we compared characteristics between those in the inadequate and adequate health literacy groups. Those with inadequate health literacy were more often African-American, had lower levels of education, and had higher (worse) FRS. No differences were noted between the health literacy groups in age, marital status, BMI, length of sentence, type of crime (violent vs. non-violent) or multi-morbidity burden score.

Non-linear regression analysis revealed that education level, BMI, and health literacy were associated with increased CVD risk (Table 4.2). Those with higher levels of education (Wald Chi Square 14.652, OR 1.093, *p* value <.001) and higher BMIs (Wald Chi Square22.563, OR 1.051, *p* value <.001) had increased CVD risk. As health literacy increased CVD risk decreased (Wald Chi Square 9.201, OR .922 *p* value .002). For every one unit increase in education and BMI the risk of CVD increased by 9% and 5% respectively. For every one unit increase in health literacy, the risk of CVD decreased by 8%.

Discussion

In a large study of prison inmates from four state prisons, we demonstrated that health literacy is strongly and independently associated with CVD risk as assessed using the FRS. Cardiovascular disease is the number one cause of death in both the general and prison populations.[1, 4, 40] Inadequate health literacy has been linked to increased CVD risk in the general population in a study reported by Martin et al.[5] In a study of 409 American adults, the researchers[5] found that health literacy skills were predictive of CVD risk among women but not for men.[5] On the contrary, we found this association was present in a group of only men. Because our study population was solely male, we were not able to compare risk by gender. Risk profiles may be different for male and female prisoners.

Additionally we found that male prisoners were at a higher risk of CVD events than the general population. Biswanger et al.[41] found that within two weeks of release from a Washington state prison, former inmates had an age adjusted death rate 12.7 times that of the general population of state residents. The deaths were attributed to drug overdose, CVD, homicide, and suicide. Many of these preventable deaths were related to

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violence or drug use, but a lapse in treatment for chronic health conditions can be seen in CVD and infectious disease deaths in this population.[41] Health literacy is an independent predictor of increased risk for CVD and recognition of prisoners with inadequate levels of health literacy may provide insight into increased risk for early death following release from prison, providing an opportunity for intervention.

Interestingly, we found that increased education was a predictor of CVD risk. This may be due to the fact that those participants who had higher levels of education were older and were at a higher risk of CVD due to age. Age was not controlled for in the regression model due to the fact that it is included in the formula for the FRS. Further analysis revealed that there was a positive correlation between age and education level found in this study (R .244, $p < .001$). This may be a possible partial explanation for this phenomenon.

The mechanism of action between inadequate health literacy and increased risk of CVD is multi-faceted. On a personal level, institutionalization can affect the prisoner's locus of control, which may lead to disbelief in one's ability to affect change for health and wellness, and negatively affect problem-solving, self-efficacy, and self-care abilities.[42-44] Others have demonstrated that inadequate health literacy is associated with decreased use of preventive health services,[9, 45, 46] decreased self-care abilities,[13, 22, 47] and increased participation in risky behaviors such as tobacco and illicit drug use.[48]

Clinical Implications

Provision of health education to prisoners must take into account the health literacy of the inmate so ensure the effectiveness of such efforts. Adequate health education should include provision of education at a level appropriate to the health

literacy of the participant with an emphasis on the importance of individual change, internal locus of control related to health issues, as well as knowledge based information on how to prevent risk and promote health.[43, 44]

Limitations.

There are some limitations inherent when working with a prison population. Institutionalization may impact the answers provided by the prisoners, as they may fear repercussions from prison administrators if questions are answered in a manner deemed socially unacceptable. There is no way to determine if the prisoners who chose to participate in the study had differing levels of health literacy or CVD risk than those who did not.

Conclusions

Health literacy is a modifiable CVD risk factor and further studies are necessary to understand if an improvement in the ability to understand and apply health information can affect overall CVD risk. Future research should focus on the impact of an educational intervention on the improvement of health literacy and the impact on the CVD risk profile of inmates.

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Table 4.1. Sample Characteristics

	All Subjects (N= 354) Mean ± SD or n (%)	Inadequate Health Literacy NVS < 4 (n=95) Mean ± SD or n (%)	Adequate Health Literacy NVS ≥ 4 (n=259) Mean ± SD or n (%)	P Value
Age, years	36 ± 12	38 ± 10	36 ± 10	.128
Education Level, years	12 ± 2	12 ± 2	13 ± 2	< .001
Marital Status				.529
Single	228 (64.4)	63 (66.3)	165 (63.7)	
Divorced/Separated	69 (19.5)	16 (16.8)	53 (20.5)	
Widowed	6 (1.7)	2 (2.1)	4 (1.5)	
Married	48 (13.6)	12 (12.6)	36 (13.9)	
Cohabitate	3 (0.8)	2 (2.1)	1 (0.4)	
Ethnicity				< .001
African-American	122 (34.5)	47 (49.5)	75 (29.0)	
Caucasian	221 (62.4)	45 (47.4)	176 (68.0)	
Hispanic or Latino	1 (1.1)	3 (1.2)	4 (1.1)	
Native American	2 (0.6)	0 (0.0)	2 (0.6)	
Length of Sentence				.500
<10 years	27 (9.7)	9 (12.7)	18 (8.7)	
10-20 years	135 (48.4)	37 (52.1)	98 (47.1)	
21-30 years	41 (14.7)	10 (14.1)	31 (14.9)	
31-40 years	17 (6.1)	4 (5.6)	13 (6.3)	
41-50 years	8 (2.9)	0 (0.0)	8 (3.8)	
>50 years	51 (18.3)	11 (15.5)	40 (19.2)	
Incarcerated for a Violent Crime	30 (8.5)	6 (6.3)	24 (9.3)	.377
Body Mass Index (BMI)	28.4 ± 5.0	28.9 ± 5.5	28.3 ± 4.8	.358
Multi-morbidity Burden Score	3.94 ± 1.6	4.0 ± 1.8	3.9 ± 1.6	.590
Framingham Risk Score	7.3 ± 6.9	8.9 ± 8.2	6.8 ± 6.3	.027

Table 4.2.Non-Linear Regression Analysis for the Prediction of Framingham Risk Score

Variable	Unstandardized Coefficient β	Standard Error	Standardized Coefficient β	Confidence Interval	P Value
Education Level	.089	.023	1.093	1.044 - 1.144	<.001
Ethnicity	.006	.094	1.006	.836 – 1.210	.951
Marital Status	-.184	.134	.832	.640 – 1.082	.170
Body mass index	.049	.010	1.051	1.029 – 1.072	<.001
Multi-morbidity Burden	.043	.028	1.044	.988 – 1.103	.128
Length of Sentence	.000	.005	1.000	.999 – 1.001	.666
Violent Crime	-.041	.149	.960	.717 – 1.284	.781
Health Literacy	-.081	.027	.922	.875 - .972	.002
Model statistics, 1610.812, 53.681, 8, *p* value <.001.					

Chapter Five

Missed Opportunities! End of Life Decision Making and Discussions in Implantable Cardioverter Defibrillator Recipients

Introduction

Implantable cardioverter defibrillators (ICDs) are the main therapy for primary and secondary prevention of sudden cardiac arrest.[1, 2] Approximately 737,840 new ICDs and 264,824 generator replacements are performed annually worldwide.[3, 4] Many of these devices are implanted in individuals with heart failure (HF).[2] Life expectancy following diagnosis of HF is five years on average, rivalling the death rate of many aggressive forms of cancer.[2] ICD recipients will most likely die from the progression of HF or terminal illness during treatment with an ICD. As terminal illness progresses, the lifesaving defibrillation therapy may be of less importance to the patient and their family. During the active dying process, electrolyte and fluid imbalances may increase the risk of shock, at the expense of unnecessary pain and suffering for patients and family members. Approximately 33% of ICD recipients receive a shock while actively dying, which may lead to the prolongation of the death experience.[5]

Guidelines for device based therapy of cardiac rhythm abnormalities were updated by the American College of Cardiology/American Heart Association/Heart Rhythm Society (ACC/AHA/HRS) in 2008 to include discussions beginning at the time of implantation with ICD recipients regarding end-of-life (EOL) choices, including generator replacement and withdrawal of defibrillation therapy in the context of terminal illness.[6] These discussions are necessary for fully informed consent and shared decision

making with health care providers and family members to occur because decision making regarding EOL choices is a complex matter.

The decision making process could be affected by health literacy levels. Health literacy is the critical juncture between education and decision making. Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Inadequate health literacy impairs one's ability to assess risk versus benefit information, participate in plans of treatment, fully engage in self-care, and communicate choices.[7] Inadequate health literacy affects the ability to fully understand EOL care options. The main goal of EOL decision making is to explore an individual's values and preferences for care based upon a full understanding of all of the options. Ensuring that individuals and families have a full understanding of EOL care options will improve the quality of the death experience allowing for death with dignity that is congruent with beliefs and values system.

Little is known about the impact of health literacy on decision making in ICD recipients regarding generator replacement and the withdrawal of defibrillation therapy in the context of terminal illness. The purpose of this study was to explore patient knowledge of the function of the ICD at EOL, provider adherence to guidelines from the perspective of the patient regarding discussions of EOL options for ICD recipients, and the relationship between health literacy and decisiveness regarding EOL choices in the population

Thus, the specific aims of this study were to:

1. determine the level of knowledge regarding ICD function at EOL among ICD recipients

2. determine perspectives about discussions held with healthcare providers regarding EOL choice (generator replacement and withdrawal of defibrillation therapy) among ICD recipients

3. examine the relationship between health literacy and decisiveness regarding EOL choices among ICD recipients

Methods

This cross-sectional study was approved by institutional review boards at two central Kentucky universities and a hospital ethics board in Melbourne, Australia.

Participants

Participants were recruited from general cardiology, electrophysiology, and heart failure clinics of tertiary hospitals in central Kentucky and Melbourne Australia. Eligibility criteria included: ICD insertion >12 months, ability to read and speak English, no severe cognitive impairment that precluded providing informed consent, no institutionalization (i.e. nursing home placement), and no current ventricular assistive device placement. Patients who were level one status on the heart transplant list were excluded.

Procedures

Potential participants were identified by research nurses in conjunction with healthcare providers practicing in the relevant clinics. Participants were screened for eligibility and gave informed consent Participants were provided with a signed copy of

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their consent form and a paper copy of the study questionnaires with a prepaid addressed envelope for completion and return at their convenience. Participants were also offered the opportunity to complete the survey online or in the clinic if they chose to do so.

Measures

The study questionnaires consisted of a sociodemographic survey; the Experiences, Attitudes, and Knowledge of End-of-Life Issues in Implantable Cardioverter Defibrillator Patients Questionnaire' (EOL-ICDQ); the Hospital Anxiety and Depression Scale (HADS); and the Newest Vital Sign (NVS). The sociodemographic questionnaire included questions of age, gender, ethnicity, history of shock and generator replacement.

ICD Knowledge and Experiences

The EOL-ICDQ is a 39 item instrument developed in Sweden to measure experiences, attitudes, and knowledge of EOL issues in ICD recipients. The instrument has known validity and reliability in ICD recipients.[8] Two items from the experiences subscale were used in the analysis of discussions with healthcare providers 'Have you discussed what a change of battery involves with your ICD doctor or nurse' and 'Have you discussed what turning off the shocks in your device involves with your ICD doctor or nurse?' Participants had the option of choosing yes/no/or decline to answer.

Knowledge of the ICD was measured using the 11 item knowledge subscale of the EOL-ICDQ. True/false/don't know answers are chosen by the respondent to statements (e.g. to turn off the ICD shocks is the same as active euthanasia; an ICD always delivers shocks at the end of life). The correct answers are summed for a total

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value of 0-11, with higher scores indicating a higher level of ICD knowledge. The Cronbach's alpha for the ICD knowledge subscale in this study was 0.741.

Decisiveness/Indecisiveness was measured by answers yes/no/cannot take a stand to the following question scenarios 'I want to have the battery in my ICD replaced: even if I am seriously ill and suffering from another disease' and 'I want to keep the shocks in my ICD: even if dying of cancer or another serious disease'.

Anxiety and Depressive Symptoms

The Hospital Anxiety and Depression Scale (HADS) is a 14-item instrument that includes two subscales that measure anxiety and depression (7 items each). Scores on each subscale range from 0 to 21 where higher scores reflect higher levels of anxiety or depressive symptoms. The reliability and validity of the HADS has been demonstrated in multiple populations.[9] The Cronbach's alpha for the overall scale in our study was 0.844 with the anxiety and depressive subscale Cronbach's alpha 0.787 and 0.739 respectively.

Health Literacy

Health literacy was measured in this study using the Newest Vital Sign (NVS). The NVS is a 6-item questionnaire used to assess the ability to read and apply information from a nutrition label that can be completed quickly in the clinical setting.[10] Scores range from 0 to 6 and represent the number of questions answered correctly, with higher scores indicating higher levels of health literacy. Scores of 4 or more correct answers indicate adequate health literacy.[10] This instrument has been found to be valid and reliable in multiple populations. The Cronbach's alpha for this instrument in our study was 0.991.

Analysis

All analyses were conducted using SPSS, version 22. Characteristics were compared between categories (yes/no/can't take a stand) regarding generator replacement and defibrillation therapy withdrawal using *t*-tests and x^2 tests.

Knowledge of the ICD at EOL was examined by the percentage of incorrect answers to the questions posed on the ICD knowledge portion of the EOL-ICDQ.[8] The number and percentage of incorrect answers were further explored by comparing incorrect answers based on health literacy categories (inadequate vs. adequate) using x^2 tests.

ICD recipients' perspectives of conversations with healthcare providers regarding generator replacement and the withdrawal of defibrillation therapy were examined by asking if they had spoken with their healthcare provider about these specific topics. The numbers and percentages of those who answered yes regarding these discussions with their healthcare provider were further explored by comparing the reports of discussions within health literacy categories using x^2 tests.

Multinomial regression was used to determine whether health literacy was a predictor of attitudes toward generator replacement and withdrawal of defibrillation therapy (yes/no/can't take a stand) in the context of terminal illness while controlling for sociodemographic variables (gender, age, ethnicity), psychosocial variables (anxiety and depression), and ICD related variables (shock experience, generator replacement, and ICD knowledge).Assumptions for multi-nomial regression were tested and none were violated.

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Sample

A total of 274 individuals participated in the study. Two hundred forty of the participants for whom data for all of the variables of interest was complete were included in this analysis. There were no significant differences on sociodemographic or clinical variables between those who were included and those who were not. The mean age of the overall sample was 62 ± 14 years, 28% of participants were female and 16.7% self-identified as a minority (Table 5.1). Thirty five percent had a history of a previous shock and 30.4% had experienced generator replacement.

There were differences between individuals with inadequate and adequate levels of health literacy (Table 5.1). Those with inadequate levels of health literacy were older (64 ± 13 vs. 59 ± 14, *p* value .002), more often minorities (23.3% vs. 10.0%, *p* value .011), were less likely to have had the ICD generator replaced (23.8% vs. 38.2%), had lower levels of ICD knowledge (5.00 ± 2.80 vs. 6.40 ± 2.93, *p* value < .001), and had lower levels of health literacy (1.28 ± 1.17 vs. 5.016 ± 0.85, *p* value <.001).

ICD Knowledge

Misconceptions regarding the ICD were apparent in the overall population. Incorrect answers on the ICD Knowledge portion of the EOL-ICDQ ranged from 20-62% per question (Table 2). Nearly 40% of individuals believed that defibrillation therapy was the same as active euthanasia and that the therapy could be turned off without their knowledge. Sixty-two percent of participants believed that the ICD always delivers a shock at the end of life and that if defibrillation therapy is withdrawn that the device no

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longer functions as a pacemaker. Twenty percent of those asked believed that once defibrillation therapy was withdrawn, the heart would cease to beat. Thirty-eight percent of people believed that the device must be removed surgically to withdrawal defibrillation therapy and 37% believe that once the defibrillation therapy is withdrawn it cannot be resumed.

There were notable differences in ICD knowledge based on health literacy category. Those with inadequate levels of health literacy were more likely to answer ICD knowledge questions incorrectly. They incorrectly believed that the ICD must be removed to disable defibrillation therapy (46.2% vs. 28.4%. *p* value, .005), that once disabled ICD shocks could not be enabled again (43.1% vs. 29.4%, *p* value, .029), that turning off defibrillation therapy was the same as active euthanasia (46.9 % vs. 26.6%, *p* value, .001), that ICD shocks could not be temporarily disabled temporarily by magnet (62.3% vs. 45.0%, *p* value, .007), that the device's function would worsen as the battery began to deplete (69.2% vs. 43.1%, *p* value, $\leq$ .001), and that when the ICD shocks were turned off that the pacemaker function ceased (71.3% vs. 49.5%, *p* value, .001).

Discussions with Healthcare Providers

Sixty-three percent of participants reported discussions with their healthcare provider regarding generator replacement. Individuals within the inadequate health literacy category reported more often that discussions with their health care provider regarding a generator change had not taken place (45.4% vs. 28.2%, *p* value .006).

Twenty-four percent of participants reported discussions with their healthcare provider about withdrawal of defibrillation therapy. Individuals within the inadequate

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health literacy category reported more often that discussions with their health care provider regarding a defibrillation therapy withdrawal had not taken place (81.5% vs. 70%, *p* value .036).

Predictors

Multinomial logistic regression was performed to assess health literacy as a predictor of decisiveness regarding EOL choice, while controlling for other variables. Models were developed for both the generator replacement and withdrawal of defibrillation therapy scenarios (Tables 5.3-5.6) Both models contained nine variables (gender, age, ethnicity, shock experience, generator replacement, ICD knowledge, and health literacy). The models for the generator replacement scenario (x^2[18, N=240]-47.571), *p*, < .001, and the withdrawal of defibrillation therapy scenario (x^2[18, N=240]-29.832), *p*, .039) were statistically significant. The reference category for both analyses were those participants who answered yes to the EOL scenarios. Results are presented as odds for answering no and can't take a stand by scenario question and are presented below.

Generator Replacement

Compared to those participants who would choose to replace the generator in the context of terminal illness; ethnicity, anxiety, depression, shock experience, ICD knowledge, and health literacy were significant predictors of choosing not to replace the ICD generator (Table 5.3) . Compared to non-Caucasians, Caucasians have a 5 fold increase in the odds of choosing not to replace the generator. Those who have not had a shock have a 54% increase in the odds of choosing not to replace the generator. For every

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one unit increase in anxiety and health literacy scores the odds of choosing not to replace the generator are decreased by 13% and 17% respectively. For every one unit increase in the depression score and ICD knowledge score the odds of choosing not to replace the generator are increased by 19% and 16% respectively.

Compared to those participants who would choose to replace the generator in the context of terminal illness, gender, anxiety, and depression were significant predictors of indecisiveness regarding ICD generator replacement (Table 5.4). Compared to women, the odds of being indecisive regarding replacement of the ICD generator in the context of terminal illness is decreased by 56% for men. For every one unit increase in the anxiety and depression score the odds of indecisiveness regarding generator replacement are increased by 15% and 17% respectively.

Defibrillation Therapy Withdrawal

Compared to those participants who would choose to maintain defibrillation therapy in the context of terminal illness, gender and ICD knowledge were significant predictors of choosing to withdraw defibrillation therapy in the context of terminal illness (Table 5.5). Compared to women, the odds of choosing to withdraw defibrillation therapy were 57% less for men and for every one unit increase in the ICD Knowledge score, the odds of choosing to withdraw defibrillation therapy are increased by 13%.

Compared to those participants who would choose to maintain defibrillation therapy in the context of terminal illness, gender and depression were significant predictors of indecisiveness regarding the withdrawal of defibrillation therapy (Table5.6). Compared to women, the odds of indecisiveness regarding the maintenance of

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defibrillation therapy were 75% less for men. For every one unit increase in the depression score, the odds of indecisiveness regarding the maintenance of defibrillation therapy increased by 13%

Discussion

ICD Knowledge

We found that ICD recipients held alarming misconceptions regarding the function of the ICD at EOL, and that individuals with inadequate health literacy were more likely to hold these misconceptions. These misconceptions may affect the decision making process related to EOL choices ultimately interfering with optimal care. Increased ICD knowledge was found to be a predictor of choosing not to replace the ICD generator and to not withdraw defibrillation therapy, which are incongruent results. Choosing not to replace the generator in the context of terminal illness is indicative of understanding the potential of unnecessary shocks that could extend the dying process, whereas choosing to maintain defibrillation therapy is not. Educational interventions should focus on explaining the function of the ICD and how it affects the dying process. An understanding of these facts is lacking in a significant number of ICD recipients and a full comprehension of the device function may impact EOL choices. When provided with full details of the function of the ICD at EOL, a majority of people choose to forego generator replacement and withdraw defibrillation therapy in the context of terminal illness. Dodson et al.[11] found that when provided information regarding the function of the ICD that 71% of patients would choose to withdraw defibrillation therapy at EOL. Individuals should have a full understanding of all of the options regarding life-

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saving/extending devices so that they may make informed decisions congruent with their value system.

Discussions with Healthcare Providers

Guidelines presented by the ACC/AHA/HRS in 2008 recommend in depth discussions regarding the function of the ICD and its impact on EOL.[6] According to the perspective of the ICD recipient, adherence to the guidelines regarding EOL discussions was minimal as most patients report that these discussions with their healthcare provider have not taken place. The healthcare provider's role in the decision making process is to present the facts, risks, and benefits in a concise and understandable manner. This allows for an exploration of values and preferences for care based upon a complete understanding of all of the options.

Exploration of the roles of providers and recipients in these discussions have identified barriers to full discussion of the impact of the ICD at the EOL. Raphael et al.[12] presented the results of a study that identified the following barriers to the discussion of ICD deactivation; the recipients' understanding of the device and the healthcare providers' willingness to discuss the topic.

ICD recipients often overestimate the benefit of the ICD.[12] Goldstein et al.[13] reported that in a focus group of 15 ICD recipients, none of the participants reported having discussions with healthcare providers regarding the withdrawal of defibrillation therapy and all of the participants believed the ICD was exclusively beneficial. Many recipients feel the healthcare provider will bring up the topic of EOL choices when the

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time arises. If the healthcare provider does not initiate the discussion of EOL choices due to discomfort with the topic the patient may infer that it is not an important.[14]

Predictors of choice in EOL decision-making

Adequate health literacy was a predictor of choosing to replace the generator in the context of terminal illness but was not a significant factor in relation to choices regarding defibrillation therapy withdrawal. Health literacy affects the application of ICD knowledge to decision making but health literacy in and of itself was not sufficient to predict decisiveness regarding EOL choices in each model. Further exploration of health literacy as a mediator or moderator of ICD knowledge and EOL decision-making is warranted to better understand the relationship of these variables.

The scenarios regarding EOL choices in this study were hypothetical and it is important to understand that as health conditions change, so may an individual's perception of what constitutes quality of life. Decisions regarding EOL care may change over time based upon severity of illness and the progression of disease in an individual. Living a life of quality can take on different meaning as death looms closer.[15]

Additionally we found that women were at risk for disparate EOL experiences regarding ICDs. Female gender was a predictor of indecisiveness in choosing to replace the generator and withdraw defibrillation therapy in the context of terminal illness. These findings echoed those of Thylen et al.[16] in the Swedish ICD population. Interventions to target those individuals who are more likely to be indecisive may be beneficial in reducing these disparities related to gender.

Additionally, we found that Caucasians were 5 times more likely to choose not to replace the generator in the context of terminal illness. This finding puts minorities at a higher risk of a prolonged death experience, by aggressively treating lethal arrhythmias. Multiple studies have indicated that minorities prefer more aggressive treatments at EOL[17]. However, Volandes et al (2008)[18] found that inadequate health literacy in minorities was actually the impetus for this choice. This finding again illustrates the potential of health literacy as a mediator/moderator of outcomes related to EOL choices.

We found that psychosocial comorbidities also affect the EOL decision making process of ICD recipients, particularly by increasing the odds of indecisiveness. Anxiety may cause an individual to feel frozen, thereby rendering them unable to make a decision. Individuals experiencing depression often exhibit negative thinking which may cloud the decision making process[19] Anxiety and depression have been shown to impact the quality of life in ICD recipients[20] and the results of this study indicate that these comorbid conditions can impact the quality of the death experience as well. ICD recipients should be screened for anxiety and depression and be referred to psychiatric providers for appropriate treatment.

Those who have not had a shock have a 54% increase in the odds of choosing not to replace the generator. Oftentimes those who have had a shock feel that the device will save them from death of all causes.[21, 22] "It saved my life and I don't want to live without it" is a common refrain of ICD recipients who have experienced a shock[21]. This overestimation of the benefits of the device may lead to impaired decision making.

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Limitations

Limitations include the cross sectional nature of this study particularly in light of the dynamic nature of EOL choices. EOL choices in this study were presented as hypothetical scenarios. Actual decision making related to the ICD at the EOL may differ from a hypothetical choice during a relatively stable time in the trajectory of device treatment.

Clinical Implications

Advanced care planning for ICD recipients is lacking in current practice. There is a need for thorough communication regarding EOL choices in ICD recipients prior to implant and throughout the trajectory of illness. Further research should focus on educational and counselling interventions to improve understanding of the function of the ICD and its impact on the quality of life during ICD therapy, as well as advanced directives specific to the ICD regarding generator replacement and the withdrawal of defibrillation therapy in the context of terminal illness.

Conclusion

Social determinants of health including gender, race, health literacy, psychosocial comorbidities, as well as ICD knowledge affect the EOL decision making process in ICD recipients. These issues should be included in planning for further research and interventions in this population to improve understanding of the function of ICDs and to reduce disparities in the quality of life and the death experience is this population.

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Table 5.1. Participant Characteristics*				
	All Participants N= 240	Inadequate Health Literacy NVS $\leq$ 3 n=130	Adequate Health Literacy NVS $\geq$ 4 n=110	P Value**
Location				.639
US	178 (74.2)	98 (75.4)	80 (72.7)	
Australia	62 (25.8)	32 (24.6)	30 (27.3)	
Gender				.508
Female	67 (27.9)	96 (73.8)	77 (70.0)	
Male	173 (72.1)	34 (26.2)	33 (30.0)	
Age	62 ± 13	64 ± 13	59 ± 14	.002
Ethnicity				.011
Caucasian	200 (83.3)	101(77.7)	99 (90.0)	
Minority	40 (16.7)	29 (23.3)	11 (10.0)	
Anxiety	5.02 ± 3.63	4.50 ± 3.64	5.32 ± 3.49	.084
Depression	4.24 ± 3.51	3.93 ± 3.15	4.55 ± 3.86	.183
Previous Shock	84 (35.0)	43 (33.1)	41 (37.3)	.497
Generator Replacement	73 (30.4)	31 (23.8)	42 (38.2)	.016
ICD Knowledge	5.57 ± 2.96	5.00 ± 2.80	6.40 ± 2.93	< .001
Health Literacy	3.07 ± 2.21	1.28 ± 1.17	5.16 ± 0.85	< .001
• *Data presented in table as n (%) or mean $\pm$ SD • ** Pearson Chi square test used to determine differences between categorical variables and t-test used to determine differences between continuous variables. An a priori value of .05 was used to determine significance				

	All Participants N= 240	Inadequate Health Literacy n= 130 n (%)	Adequate Health Literacy n= 110 n (%)	P Value
Table 5.2. Incorrect Answers on ICD Knowledge Questionnaire by Health Literacy Category				
In order to turn off the defibrillating shocks in an ICD, the ICD must be removed by surgery	91 (38.1)	60 (46.2)	31 (28.4)	.005
When the ICDs defibrillating shocks have been turned off, they can't be turned on again	88 (36.8)	56 (43.1)	32 (29.4)	.029
When an ICDs defibrillating shocks are turned off, the heart stops beating	48 (20.1)	29 (22.3)	19 (17.4)	.349
An ICDs defibrillating shocks can be turned off without my or my relative's knowledge	93 (38.9)	49 (37.7)	44 (40.4)	.673
To turn off the defibrillating shocks in an ICD is the same as actively ending my life	90 (37.7)	61 (46.9)	29 (26.6)	.001
In order to turn off the ICDs defibrillating shocks, a temporary deactivation can be done via a magnet	130 (54.4)	81 (62.3)	49 (45.0)	.007
In connection with the defibrillating shock, the shock is also transferred to those persons having direct bodily contact	129 (54.0)	71 (54.6)	58 (53.2)	.828
When an ICD's battery voltage is beginning to wear, even the ICD's functioning worsens	137 (57.3)	90 (69.2)	47 (43.1)	< .001
An ICD always delivers defibrillating shocks in connection with end-of-life	147 (61.5)	83 (63.8)	64 (58.7)	.417
In order to turn off the ICDs defibrillating shocks a reprogramming can be performed by an external programmer	72 (30.1)	46 (35.4)	26 (23.9)	.053
When the ICD's defibrillating shocks are turned off, the pacemaker function in the ICD is also deactivated	146 (61.3)	92 (71.3)	54 (49.5)	.001

Table 5.3. Multinomial Regression Generator Replacement Reference group: Yes to generator change in the context of terminal illness					
	No to generator change			**Indecisive**	
	Odds Ratio (95% CI)	P Value		Odds Ratio (95% CI)	P Value
Male gender	.441 (.193 – 1.011)	.053		.448 (.203 - .991)	.047
Age	.053 (.984 – 1.047)	.336		.995 (.967 – 1.025)	.747
Caucasian	5.068 (1.319 – 19.473)	.018		2.641 (.892 – 7.818)	.079
Anxiety	.877 (.787 - .977)	.017		.845 (.762 - .936)	.001
Depression	1.188 (1.073 – 1.315)	.001		1.171 (1.062 – 1.291)	.002
Shock	.464 (.219 - .981)	.045		.872 (.400 – 1.901)	.731
Generator Replacement	1.120 (.500 – 2.509)	.783		.901 (.411 – 1.974)	.794
ICD Knowledge	1.161 (1.003 -1.343)	.046		.924 (.811 – 1.054)	.241
Health Literacy	.838 (.704 - .997)	.046		1.000 (1.00 – 1.001)	.578

Table 5.4: Multinomial Regression Defibrillation Therapy Maintenance Reference group: Yes to keeping shocks in the context of terminal illness					
	No to keeping shocks			**Indecisive**	
	Odds Ratio (95% CI)	P Value		Odds Ratio (95% CI)	P Value
Male gender	.437 (.210 - .911)	.027		.252 (.111 – .572)	.001
Age	1.005 (.980 – 1.030)	.281		.999 (.971 – 1.029)	.965
Caucasian	2.089 (.862 – 5.066)	.103		2.073 (1.029 – 2.151)	.159
Anxiety	.942 (.860 – 1.032)	.201		.918 (.832 – 1.014)	.091
Depression	1.074 (.980 – 1.177)	.125		1.135 (1.029 – 1.251)	.011
Shock	.952 (.491 – 1.846)	.885		.811 (.376 – 1.748)	.592
Generator Replacement	1.542 (.787 – 3.024)	.207		1.810 (.804 – 4.076)	.152
ICD Knowledge	.087 (.077 - .093)	.038		1.010 (.885 – 1.153)	.881
Health Literacy	1.001 (.993 – 1.010)	.793		1.001 (.993 – 1.200)	.782

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Chapter Six

Social Determinants of Health, and Perceived Health Status in ICD Recipients in Central Appalachian

Introduction

Medical advances including medications and implanted cardioverter defibrillators (ICD) have decreased the morbidity and mortality of those individuals with a history of, or risk for, sudden cardiac death. Despite these advances in medical science there remain disparate outcomes in morbidity, mortality and other outcomes related to CVD, and these disparities have been linked to social determinants of health (SDH).[1, 2] Social determinants of health are the circumstances in which people live out their lives and include gender, race, socioeconomic status, physical environment, and health literacy.[3] These circumstances are often related to distribution of power, money, and resources and can have lasting effects on health over the life course of multiple generations.[3-5]

The Central Appalachian region of Kentucky is well known for disparate social circumstances. All of the Appalachian counties in Kentucky are designated as distressed or at risk by the Appalachian Regional Commission.[6-8] Additionally, nearly one third of the 100 poorest counties in the US are located in the Central Appalachian region of Kentucky.[9] Lower levels of education, lower salary levels, and the highest levels of unemployment in the country impact the health of this population significantly.[10-12]

Perceived health status is a subjective measure of overall health. Multiple investigators have indicated that perceived poor health status is a predictor of morbidity, disability, and mortality.[13, 14] Social determinants of health are associated with perceived

health status in that those with worse economic and social conditions commonly perceive that their health is poor, and commonly also have worse health outcomes.[15, 16] High levels of morbidity, disability, mortality, and austere social conditions are apparent in the Central Appalachian region of Kentucky. However, little is known about the intersection of these variables in ICD recipients who reside in Central Appalachia.

The purpose of this study was to examine the SDH and perceived health status among Appalachian and non-Appalachian ICD recipients. The specific aims were to: 1) compare SDH and perceived health status of ICD recipients in Central Appalachia with those of ICD recipients who reside in other areas of Kentucky; 2)) examine predictors of perceived health status from among SDH.

Methods

This cross sectional study was approved by institutional review boards at two central Kentucky universities

Participants

Participants were recruited from general cardiology, electrophysiology, and heart failure specialty clinics in two university associated hospitals in Kentucky. Eligibility criteria included: ICD insertion > 12 months, ability to read and speak English, no severe cognitive impairment that would affect the ability to understand the study and provide fully informed consent, no institutionalization (e.g.. nursing home), and no current ventricular assistive device placement. Patients who were listed as level one status on the heart transplant list were excluded.

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Procedures

Potential participants were identified by a research nurse in coordination with healthcare providers and approached during scheduled clinic appointments. The study was fully explained to eligible ICD recipients to whom a paper copy of the informed consent was provided. Those who chose to participate completed the formal consent process and were provided with a signed copy of their consent, and a paper copy of the study questionnaire with a postage paid envelope for return of the questionnaire. Participants were also provided the opportunity to complete the questionnaire online based on their personal preference.

Measures

Sociodemographics and Clinical Data

Sociodemographic information was collected using a self-report questionnaire. Information collected included place of residence, gender, age, education, ethnicity, marital status, and employment status. Clinical variables were also self-reported and included length of time since the first ICD was implanted and the indication (primary vs. secondary prevention), generator replacement, history of ICD shock, and overall ICD experience.

Psychosocial Comorbidity

The Hospital Anxiety and Depression Scale (HADS) was used to measure symptoms of anxiety and depression. The HADS consists of two 7-item subscales that measure anxiety and depression. Scores on each subscale range from 0-21, with higher

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scores indicating higher levels of anxiety and depression symptoms. The instrument has been found to be valid and reliable among multiple populations.[17-19] The Cronbach's alpha was acceptable for the anxiety and depression subscales in this study, .881 and .893 respectively.

Health Literacy

Health literacy was measured in this study using the 6-item Newest Vital Sign (NVS). This instrument measures the ability to read and apply information from a nutrition label. Scores range from 0-6 with higher scores indicating higher levels of health literacy. The commonly accepted cut points are ≤ 3 indicating inadequate health literacy and ≥ 4 indicating adequate health literacy.[20] This instrument has been found to be valid and reliable in multiple populations and an acceptable Cronbach's alpha of .841 was found for this study.

Perceived Health Status

Perceived health status was measured using a five point scale. Participants were asked to rate their overall health on a scale of very good, good, fairly good, poor, or very poor. The one question assessment of perceived health status comes from the Medical Outcomes Study SF-36 and has been utilized in multiple studies and has been found to be valid and reliable.[13, 14]

Analysis

All analyses were completed using SPSS version 22. Sociodemographic, clinical, health literacy levels, and perceived health status were compared between individuals

based upon primary residence identified as an Appalachian county compared to other counties of residence within the state using t-tests and x^2 tests. Multinomial regression with all five categories of perceived health status was not appropriate as many of the categories had small numbers. Preliminary results indicated most differences occurred between health status perceived as good versus poor. Thus, the categories were dichotomized to the following two categories: very good/good/fairly good and poor/very poor. Logistic regression was used to determine the predictive ability of SDH (gender, age, education, Appalachian residency, health literacy, marital and employment status) for perceived health status while controlling for psychosocial comorbidity.

Results

A total of 201 ICD recipients from the US participated in this study. Twenty-eight percent (n=56) of the US participants reside in Central Appalachia. There were noticeable differences between the Appalachian residents and those who lived in other areas of the state (Table6.1). More of the Appalachian participants were Caucasian (93% vs. 81%, p value, .036), had higher levels of education (13$\pm$ 5 vs. 11 $\pm$ 6 years, p value, .002),and were less often employed (8.9% vs. 22.2%, p value .027). Insurance coverage was not used as a variable in the analysis as 99% of the participants were covered with private or government insurance (Medicare and Medicaid). Appalachian participants reported higher numbers of generator replacement (42.9% vs. 27.0%, p value .026), fewer reported primary prevention as an indication for implant (55.4% vs. 71.4%, p value, .025), and reported a longer time since first implant (8 $\pm$ 5 vs. 7 $\pm$ 4 years, p value, .043). The participants who resided in Appalachia reported increased symptoms of anxiety (6.28 $\pm$ 3.69 vs. 4.67 $\pm$ 3.53, p value, .004), as well as depression (5.46 $\pm$ 3.76 vs. 3.83 $\pm$ 3.32, p

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value, .003). Appalachian participants perceived their overall health as very good/good/fairly good less often and as poor/very poor more often than participants from other regions in the state (Table 6.1).Logistic regression analysis was conducted to predict perceived poor health status in ICD recipients (Table 6.2). The overall model was significant ($p < .001$) with Hosmer and Lemeshow test results demonstrating good fit of the data ($p=.372$). The model correctly classified 83.2% of the cases overall. Compared to participants in Central Appalachian, participants from other areas of the state were 65% less likely to describe the overall state of health as poor/very poor. Compared to those who were retired/disabled/unemployed, those who were employed were 88% less likely to describe the overall state of their health as poor/very poor. For every one unit increase in the score of depressive symptoms and health literacy score participants were more likely to describe the overall health status as poor/very poor (36% and 22% more likely respectively).

Discussion

Social determinants of health predict perceived poor health status in ICD recipients. Residential status in the Central Appalachian region of Kentucky, not working outside the home, higher levels of health literacy, and comorbid depression were predictive of perceived poor/very poor health status.

The Central Appalachian region of the United States is the most socioeconomically austere area of the country.[7-9] The region's high poverty rate has been linked to minimal industry, limited household mobility, and low education levels in the area as well as remoteness from cities.[21] The social and physical environment is lacking

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in vital resources for health promotion and wellness and individuals in the Central Appalachian region share many risk factors and exposures that lead to poor health outcomes. Documented risk factors for poor health in the Appalachian population include higher levels of obesity,[22, 23] increased tobacco use,[22] sedentary lifestyle,[24] poor diet,[23] increased prevalence of psychosocial comorbidities,[25] and increased prevalence of diabetes.[26]

We found significant differences in sociodemographic variables in the Appalachian subset of the study sample. A higher percentage of Caucasians and lower levels of employment were present in this sample and are commonly noted in descriptions of the Appalachian population.[7-9] Interestingly, in this study we found higher levels of education for those individuals who live in Central Appalachia, which is contrary to most reports of the region.[7, 9] This may be due in part to the makeup of the individuals who were able to leave their regional home to seek healthcare at a university based facility in Central Kentucky. Many of the Appalachians who participated in this study lived up to 200 miles from the hospital in which they sought care, which would require resources such as transportation and sufficient monies for travel.

We found that those individuals who were employed were much less likely to describe their overall health as poor/very poor than those who were retired/disabled/unemployed. This may be related to the physical functioning required to maintain employment. Those individuals who are well enough to continue working have better health overall, both subjectively and objectively[27] Employment has been linked to better physical and mental health overall while chronic disease, mental health issues, and

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perceived poor health have been found to increase the transition from paid employment to retirement/disability/unemployment.[28]

Additionally, we found that as health literacy increased participants were more likely to rate their overall health status as poor/very poor. This may be due in part to participants with higher levels of health literacy recognizing the severity of their symptoms and as such may have a better understanding of health limitations.[29-31] Individuals with higher levels of health literacy are better able to gauge the severity of their illness and manage their chronic health conditions.[29, 32]

The Appalachian subset also reported higher levels of anxiety and depressive symptoms. Higher levels of psychosocial comorbidities have been linked to poor outcomes in individuals with CVD and point to a potential pathway of disparities in the region.[25, 33] Comorbid depression predicted perceived poor health status in this study. There is a known higher prevalence of depression in both ICD recipients[34] and Appalachian residents.[25] A higher prevalence of depression in ICD recipients who reside in Appalachia is therefore expected. Depression affects CVD outcomes in multiple ways, both physically and psychologically.[35] Individuals with depression have increased levels of cytokines, particularly tumor necrosis factor (TNF) α, and interleukin (IL)1β, indicating an activation of the inflammatory response system which leads to worse CVD outcomes.[36] Additionally depression has been shown to decrease adherence to treatment regimens, decrease health promotion activities, and decrease motivation for behavior change necessary to improve CVD outcomes.[35, 37] Depression has been under recognized and undertreated in CVD patients despite AHA recommendations for depression screening in individuals with CVD.[35] Recognition of symptoms and referral for

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depression treatment may help to improve the outcomes of ICD recipients, particularly those in Central Appalachia.

Analysis of clinical variables of the study sample led to the unexpected finding of higher numbers of generator replacements, a greater number of years since original implant, and a higher incidence of secondary prevention as an indication for ICD implantation in the Appalachian subset of the study sample. The increased number of generator replacements may be directly related to the longer device dwell time. However the difference in implant indication, is not as readily explainable.

In this study sample, ICDs were more frequently implanted for secondary prevention of sudden cardiac arrest than for primary prevention. There are multiple potential explanations for this phenomenon. Increased prevalence of CVD in the Appalachian population may lead to a significantly higher number of sudden cardiac arrests. Healthcare providers and healthcare facilities may be slower in catching up to updated guidelines for ICD implantation, which included the indication for primary prevention in 2006.[38]Those individuals who had experienced a lethal arrhythmia in the past may have been more motivated to seek care in a tertiary care facility, despite having to travel a significant number of miles.

To our knowledge, this phenomenon has not been recognized or discussed in the literature. There has been recognition of medical practice variations in the treatment of individuals with heart failure often based on the quality of hospitals and providers in different service areas[39] but nothing specific for ICD recipients in the Appalachian region of the US. Further research on this issue is indicated as decreased access to primary

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prevention ICDs may lead to disparate outcomes and unnecessary deaths in this population.

This study was cross-sectional in nature and as such has the inherent limitations of inability to indicate cause and effect, or absolute directionality in associations among variables. Additionally, data was collected at a tertiary care facility often as far as 200 miles from the participants' place of residence which may affect the generalizability of the data. Other Appalachian ICD recipients may have unable to travel to the facility, particularly those who do not have transportation or insurance. These ICD recipients may have sought care closer to home. The results of this study should be interpreted with that knowledge.

Social determinants of health predict perceived poor health status in ICD recipients with worse overall perceived health in ICD recipients who reside in Central Appalachia. Recognition of health disparities in this population is the first step to the development of interventions to improve the overall health and well-being of ICD recipients. To be effective, interventions targeting health promotion and wellness in this population should be based upon Purnell et al.'s[40] recommendations focusing on the individual patient, social support networks, health care providers/organizations, and community/policy level change. Educational and counseling interventions should also take into account the health literacy levels of participants in order to produce change and improve overall health, both subjectively and objectively.

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Table 6.1. Sample Characteristics of Implantable Cardioverter Defibrillator (ICD) Recipients Compared by Appalachian Residential Status				
	All Participants N=241	Appalachian Residents n=56	Non-Appalachian Residents n=185	P Value
	M $\pm$ SD or N (%)	M $\pm$ SD or N (%)	M $\pm$ SD or N (%)	
Gender				.763
Male	177 (73.4)	42 (75.0)	135 (73.0)	
Female	64 (26.6)	14 (25.0)	50 (27.0)	
Age (Years)	61 $\pm$ 14	62 $\pm$ 12	61 $\pm$ 14	.659
Education (Years)	11 $\pm$ 5	13 $\pm$ 3	11 $\pm$ 6	.002
Ethnicity				.036
Caucasian	202 (83.8)	52 (92.9)	150 (81.1)	
Minority	39 (16.2)	4 (7.1)	35 (18.9)	
Marital Status				.073
Partnered	156 (65.0)	42 (75.0)	114 (62.0)	
Not Partnered	85 (35.0)	14 (25.0)	70 (38.0)	
Employment Status				.027
Employed	46 (19.1)	5 (8.9)	41 (22.2)	
Retired/Disabled/Unemployed	195 (80.9)	51 (91.1)	144 (77.8)	
Time Since First Implant (Years)	7 $\pm$ 4	8 $\pm$ 5	7 $\pm$ 4	.043
Implant Indication				.025
Primary Prevention	163 (67.6)	31 (55.4)	132 (71.4)	
Secondary Prevention	78 (32.4)	25 (44.6)	53 (28.6)	

Generator Replacement	74 (30.7)	24 (42.9)	50 (27.0)	.024
Previous Shock	84 (34.9)	25 (44.6)	59 (31.9)	.079
Positive ICD Experience	224 (94.9)	53 (94.6)	171 (95.0)	.915
Anxiety Symptoms	5.04 ± 3.62	6.28 ± 3.69	4.67 ± 3.53	.004
Depressive Symptoms	4.21 ± 3.48	5.46 ± 3.76	3.83 ± 3.32	.002
Health Literacy	3.09 ± 2.21	3.38 ± 2.21	3.00 ± 2.21	.263
Perceived Health Status				.003
Very Good	28 (11.6)	3 (5.4)	25 (13.5)	
Good	52 (21.6)	8 (14.3)	44 (23.8)	
Fairly Good	104 (43.2)	21 (37.5)	83 (44.9)	
Poor	38 (15.8)	15 (26.8)	23 (12.4)	
Very Poor	15 (6.2)	8 (14.3)	7 (3.8)	

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Predictor	B (S.E)	Adjusted Odds Ratio	95% Confidence Interval	P Value
Gender	.187 (.500)	1.206	.453 – 3.237	.708
Age	-.009 (.016)	.991	.961 – 1.023	.592
Education	-.046 (.046)	.955	.873 – 1.043	.312
Appalachian Residency	- 1.049 (.445)	.350	.153 - .874	.018
Marital Status	-.159 (.448)	.853	.374 – 2.191	.723
Employment Status	-2.165 (.820)	.115	.023 - .578	.008
Symptoms of Anxiety	.022 (.072)	1.023	.894 – 1.184	.766
Symptoms of Depression	.306 (.074)	1.358	1.172 – 1.567	< .001
Health Literacy	.202 (.101)	1.224	1.102 – 1.481	.045

Table 6.2. Logistic regression identifying predictors of Perceived Health Status in ICD Recipients

The model was significant ($p < .001$) with Hosmer and Lemeshow test results demonstrating good fit of the data ($p = .372$). The model correctly classified 83.2% of the cases overall.

Chapter Seven

Summary of Findings

Background and Purpose

The overall purpose of this dissertation was to explore the relationship between social determinants of health, particularly health literacy, and disparate outcomes related to CVD in vulnerable populations. Cardiovascular disease deaths have decreased on average in the US over the past couple of decades. However, CVD remains the leading cause of death in the US and worldwide with documented evidence of worse outcomes for those who are vulnerable (ie women and minorities.[1,2] Vulnerable populations were defined in this dissertation as those who are at disparate risk of poor physical, psychological, or social health due to commonly held attributes or exposures.[3] These vulnerable populations are linked by risk and resources, impacted by social determinants of health.

Summary of Findings

Chapter two was the report of a cross-sectional study in which QOL, anxiety, and depressive symptoms were compared between genders in 3,067 ICD recipients in the Swedish ICD and Pacemaker Registry. Multiple linear regression was used to determine predictors of anxiety, depression, and QOL in men and women. A higher prevalence of anxiety symptoms in women was noted with no differences in depressive symptoms found between the genders. We discovered that most ICD recipients report a good quality-of-life, without emotional distress, but among the minority with distress, women fared worse than men. The majority of the variance in the predictive models for QOL was explained by the addition of the psychosocial variables for both genders.

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Predictors of anxiety differed for men and women in this study. In women, ICD experience, perceived control, depressive symptoms, and type D personality were predictors of anxiety. These variables were significant in men as well with additional factors that were predictive of anxiety, including younger age, and comorbidity burden. Although the prevalence of depression was similar between the genders, and factors such as comorbidity burden, and anxiety were predictors of depressive symptoms for both genders, we found that for men the ICD experience, length of time since implant, and implantation for secondary prevention were also predictive of depressive symptoms. Symptoms of anxiety and depression, perceived control, and comorbidity burden were significant predictors of QOL in both genders.

Gender disparities in relation to cardiovascular disease; its recognition, treatment, and overall impact are well documented,[2, 4, 5] but thus far little is known regarding the disparities between the genders related to ICD therapy. The results of this study echoed the findings in the literature regarding general CVD and explored the overall impact of the ICD on psychological and QOL outcomes

In the light of the results of chapter two, which indicated that comorbidities played a significant role in the QOL in ICD recipients, we decided to explore this association further. Chapter three was the report of a study in which the association between multi-morbidity burden and QOL was examined in 3,067 ICD recipients in the Swedish ICD and Pacemaker Registry. Logistic regression was used to determine predictors of QOL. Greater multi-morbidity burden was associated with lower QOL in ICD recipients.

The term multi-morbidity burden was used because the majority of ICD recipients have a high number of comorbidities that exponentially increase the burden of disease. The burden of multi-morbidity was measured using the number of co-occurring disease with a value of discomfort for each condition. Multi-morbidity burden is an important factor related to QOL, the impact of which should be discussed with potential ICD recipients prior to implant. The impact of the ICD to QOL in individuals with high levels of multi-morbidity may be significant enough of an issue to warrant a long discussion regarding risks vs. benefits of the device over the course of ICD therapy. International guidelines are in place recommending that these discussions occur,[6, 7] however, multiple studies indicate that these discussions are not happening from the perspective of the ICD recipient.[8-10]

Chapter four was the report of a study conducted to determine whether health literacy levels independently predict CVD risk in the male prison population. Three hundred and fifty four male inmates in four Kentucky state prisons who were participating in a bio-behavioral intervention to decrease CVD risk completed an assessment of health literacy and cardiovascular risk at baseline.

We found that those with inadequate health literacy were more often African-American, had lower levels of education, and had higher (worse) FRS. There was an inverse relationship between health literacy and CVD risk. As health literacy increased CVD risk decreased. These findings suggest that interventions to improve health literacy might have a substantial impact on CVD risk in this population. This study identified a link between health literacy and CVD risk in male inmates. We found that the prisoners in this study had a higher risk for CVD than the general population. Little is known about

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the relationship between health literacy and risk for CVD. A search of current literature led to only one previous study by Martin et al. that indicated a link between health literacy levels and risk of CVD.[11]

Chapter 5 was the report of a study that examined: 1) the level of knowledge of ICD recipients' regarding the function of the ICD, 2) the perspective of ICD recipients regarding discussions with healthcare providers about generator replacement and the withdrawal of defibrillation therapy in the context of terminal illness, and 3) predictors of decisiveness regarding EOL choices in ICD recipients.

Two hundred and forty ICD recipients participated in this study, the majority of whom were from the distressed region of Central Appalachia. We found that ICD recipients held alarming misconceptions regarding the function of the ICD at EOL, and that individuals with inadequate health literacy were more likely to misunderstand the device. These misconceptions may affect the decision making process related to EOL choices ultimately interfering with optimal care. According to the perspective of the ICD recipient, adherence to the guidelines regarding EOL discussions was minimal. The results of the analysis were surprising, Adequate health literacy was a predictor of choosing to replace the ICD generator in the context of terminal illness but was not a predictor of decisiveness regarding the withdrawal of defibrillation therapy. Increased ICD knowledge was a predictor of decisiveness for both generator replacement and defibrillation therapy withdrawal.

Health literacy may impact the application of ICD knowledge but the impact of health literacy in and of itself was mixed in relation to decisiveness regarding EOL

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choices in this study. Further exploration of health literacy as a mediator or moderator of ICD knowledge and EOL decision-making is warranted to better understand the relationship of these variables.

Chapter six was the report of a study that examined the relationship between SDH and perceived health status among Appalachian and non-Appalachian ICD recipients. The specific aims were to: 1) compare social conditions in which ICD recipients in Central Appalachia live and the perceived health status of this population compared to ICD recipients who reside in other areas of Kentucky, and 2) examine SDH as predictors of perceived health status.

A total of 201 ICD recipients participated in this study. Twenty-eight percent (n=56) of whom reside in Appalachian counties in Kentucky. There were differences noted between Appalachian ICD recipients compared ICD recipients in the rest of the state. More of the Appalachian participants were Caucasian, had higher levels of education, and were less often employed. Additionally, we found that the Appalachian participants were less likely to have had their ICD implanted for primary prevention purposes, had their devices implanted longer, and were more likely to have had their generator replaced. Social determinants of health predict perceived poor health status, specifically residential status in the Central Appalachian region of Kentucky, not working outside the home, higher levels of health literacy, and comorbid depression were predictive of perceived poor/very poor health status.

Impact of Dissertation on the State of the Science

This dissertation represents an important contribution the literature as little is known about the overall experience of ICD recipients. ICDs first began being used en masse in the early 1990s. Initially the use was limited to secondary prevention and then primary prevention of sudden cardiac arrest in high risk patients. It is in these primary prevention patients, currently the majority of ICD recipients, that discussions of the risk benefit balance is of particular importance. The ICD is not purely beneficial, there are risks involved in the treatment and there should be thorough discussions with potential recipients regarding the long term impact of the device on QOL.

Not all patients are offered appropriate ICD therapy, particularly women and minorities and the therapy has been utilized in patients in which it was not entirely appropriate.[4, 12] Guidelines and protocols exist for appropriate treatment however, certain patient populations are not offered or summarily refuse to have the devices implanted.[4, 13] Further research should examine reasons for disproportionate offering of the devices and reasons that some patients refuse the devices. It is important to understand why people who decide not to have devices implanted do so. Research into physician attitudes, referral, and implant practices should occur to answer some of these questions as well. Another area of interest is that of healthcare provider and patient barriers to discussions regarding EOL in device recipients.

Most research studies regarding EOL choices are hypothetical in nature and studies have shown that people often are more concerned about comfort care when not in

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the active phase of dying, but as death looms closer many people choose aggressive therapies with the intent of staying alive.[14]

Prisoners are often excluded from research due to ethical concerns. Prisoners have traditionally been considered a protected population due to the potential for coercion, questions of autonomy, and privacy difficulties.[15] However, recently concerns have been raised about the ethics of excluding prisoners from research, many of whom are minorities. The study reported in this dissertation was a report from the baseline data of a large biobehavioral education and counseling intervention to decrease CVD risk in prisoners, whom we found to have a higher risk for CVD than the general population. This study helps to pave the way for other studies to be performed with prisoners in an ethical manner.

The studies reported in this dissertation examined the impact of social determinants of health on CVD related outcomes. There is much work left to be done. The recognition of disparities is just the first step in the process. There are many reports of disparities and the resulting impact on vulnerable populations. This information needs to be utilized to target interventions that result in decreasing disparities and improving the health of vulnerable populations.

Purnell et al.[16] discussed the current state of disparities in racial/ethnic minorities, rural residents, and adults with low incomes. Health disparities research address significant multi-level social issues in access to and quality of healthcare. The author's recommend interventions at four levels to fully address health disparities in vulnerable populations Level 1) individual patient, Level 2) family friends and social support

network, Level 3) healthcare organization and provider, Level 4) policy and community.[16]

Based on the above model, effective interventions to address health disparities in prisoners should include education and counseling appropriate for the health literacy level of participants. Prisoners often lose traditional social support mechanisms such as family and friends during incarceration and inclusion of family in interventions may be difficult due to prison regulations. It may be beneficial to address other levels of social support in the prison such as religious, hobby, or educational groups. Educational programs to address the knowledge deficits of prison administration and healthcare providers in the prison system. The implementation of policies to address issues of CVD risk and wellness in the prison population are imperative.

The most effective interventions to address health disparities related to ICD recipients include education appropriate based on health literacy levels for patients and family caregivers, as well as an intervention that addresses the knowledge and practice deficits of healthcare providers, specifically regarding the issues of equitable access to appropriate treatment and discussion of EOL choices. Interventions at the policy level include specific guidelines to ensure equitable access to treatment and measures to ensure the highest levels of quality of life and quality of the death experience in ICD recipients.

Recommendations for Nursing Practice and Research

1. Identification of health literacy levels in patients

    a. Health literacy plays an important role in the application of health knowledge. It should be a consideration when planning educational interventions

2. Targeting vulnerable populations for interventions to decrease disparities

    a. The recognition of disparities in vulnerable populations is not enough. This information should be used to target at risk populations to reduce disparities

    b. The increased prevalence of anxiety and worse QOL in women living with ICD therapy should be explored further. This exploration should include counselling and educational interventions to address the specific needs of women living with ICD therapy, to overcome the disparities in psychological health outcomes and QOL.

3. The importance of recognition and treatment of anxiety and depression in ICD recipients.

    a. Psychosocial comorbidities play an important role in the QOL of ICD recipients, they have a significant impact and efforts to identify and treat patients at high risk should be a priority. Assessment of psychosocial issues should occur throughout the treatment trajectory.

4. Assessment and enhancement of knowledge and practice deficits in healthcare providers regarding health disparities in vulnerable populations.

     a. Equitable access to and quality of healthcare is a priority in health

disparities research.

Limitations

Each of the studies reported in this dissertation were cross sectional survey design studies and as such no causation can be determined. Those who were extremely depressed or anxious may not have participated leading to a participation bias. The prison setting offers a host of potential issues. Prisoners may not participate for fear that anything they say will be discovered by the administration of the prison or they may feel coerced into participating for fear of retribution from administration if they do not. Unfortunately health literacy was not measured in the Swedish study sample. The papers were included in this dissertation due to the impact of the SDH of gender and multi-morbid chronic illness.

Conclusion and Future Research Plans

Social determinants of health such as gender, race, geographic location, institutionalization, and health literacy impact outcomes related to cardiovascular health. Health literacy is one of the few modifiable SDHs, and as such provides a unique opportunity for researchers. As such, it can be utilized to identify at risk populations and as a target for intervention to decrease disparities in vulnerable populations.

1. <u>Future research plans</u> include an educational and counseling intervention for ICD recipients to Education and counseling intervention to increase knowledge of the ICD and to develop advance directives specific to the ICD to ensure a full understanding of the impact of the ICD at the EOL.

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2. Interventions to address knowledge and practice deficits of healthcare providers regarding equitable access to treatment and EOL choices.

3. Further analysis of the role of health literacy as a mediator/moderator of ICD knowledge and EOL choices

4. Further analysis of the ICD study to determine if the gender disparities are similar to the Swedish data.

5. Further analysis of the prison data to determine if the educational and counseling intervention improved the health literacy of the prisoners and the relationship of that improvement to CVD risk profiles.

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Education

Institution	Degree	Date Conferred	Field of Study
University of Kentucky	PhD	2011- Present	Nursing
Indiana Wesleyan University	MSNEd	April, 2012	Nursing Education
University of Kentucky	BSN	July, 2006	Nursing
Midway College	ADN	May, 1997	Nursing

Certifications and Licensure

Kentucky RN License # 1086504 1997 – Present

AACN Cardiac Vascular Nursing Certification 2003 – 2010

Professional Experience

Dates	Institution and Location	Academic Positions Held
January, 2015 – Present	Journal of Cardiovascular Nursing	Digital Editor
August, 2012 – January, 2015	Kentucky State University	Clinical and Classroom Instructor
August, 2011 – Present	University of Kentucky, Lexington, KY	Graduate Assistant Research and Teaching
August, 2009 – July, 2011	Midway College, Midway, KY	Clinical and Classroom Instructor

Clinical Positions

Dates	Institution and Location	Clinical Positions Held
August, 2011 – July, 2014	University of Kentucky Chandler Medical Center Lexington, KY	Staff Nurse Diagnostic Radiology (Adult and Pediatric)
January, 2008 – November, 2009	St. Joseph Hospital Lexington, KY	Clinical Manager and Rapid Response Nurse
April, 2004 – August, 2007	University of Kentucky Chandler Medical Center Lexington, KY	Staff Nurse Cardiac Catheterization and Electrophysiology Lab (Adult and Pediatric); Research Nurse
February, 2003 – April, 2004	Frankfort Regional Medical Center Frankfort, KY	Staff Nurse ICU/CCU/ER
February, 2003 – April, 2004	St. Jude Medical Lexington, KY	Pacemaker and ICD Device Specialist
June, 2000 – February, 2003	Kentucky Cardiovascular Group Lexington, KY	Private Practice Nurse Pacemaker and ICD Device Clinic Manager
April, 1998 – October, 2000	Central Baptist Hospital Lexington, KY	Staff Nurse Post-Intervention/ Telemetry Unit
May, 1997 – April, 1998	St. Joseph Hospital Lexington, KY	Adult and Pediatric Medical Surgical Unit

Awards and Honors

Year	Award
2016	Kentucky Opportunity Fellowship University of Kentucky
2015	Saha Award for Cardiovascular Research and Education
2015	Keith and Juli Daniels Scholarship University of Kentucky
2015	Top Ten Reviewer: European Journal of Cardiovascular Nursing
2014	Keith and Juli Daniels Scholarship University of Kentucky
2013	New Opportunity Fund Scholarship University of Kentucky

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2013	Keith and Juli Daniels Scholarship University of Kentucky
2012	University of Kentucky College of Nursing Celebrating 50 Scholarship
2012	Best Oral Graduate Podium Presentation- 8th Annual University of Kentucky College of Nursing Student Scholarship Showcase
2006	University of Kentucky Chandler Medical Center CORE Award- Respect
1997	St. Joseph Hospital Nursing Graduate of the Year
1996	VFW Nursing Clinical Award and Scholarship

Publications

Miller, J., Thylen, I, & Moser, D.K. (2016). Gender disparities in symptoms of anxiety, depression, and quality of life in defibrillator recipients. *Pacing and Clinical Electrophysiology, 39*(2), 149-159.

Miller, J., Thylen, I., Biddle, M.J., Bailey, A.L., Hammash, M.H., and Moser, D.K. (2015). Abstract 11135:Missed Opportunities! End-of-Life discussions and implantable cardioverter defibrillator patients. *Circulation, 132,* A11135.

Strömberg, A., Fluur, C., Miller, J., Chung, M.L., Moser, D.K., & Thylén, I. (2014). ICD-recipients' understanding of ethical issues, ICD function, and practical consequences of withdrawing the ICD in the end-of-life, *PACE, 37,* 834-842.

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Miller, J. L., Chung, M., Connell, A., Bailey, A.L., Lennie, T.A., & Moser, D.K. (2012). Abstract 16038: Health literacy predicts cardiovascular risk in the male prison population. *Circulation, 126* (21 Supplement), A16038

Presentations

Date	Program Title	Sponsor	Location
Spring 2016	Miscommunication and Misperceptions: End-of-Life Issues in Implantable Cardioverter Defibrillator Recipients	Top Ten Student Posters: Southern Nursing Research Society	Williamsburg, VA

Fall 2015	Missed Opportunities! End of Life Discussions and Implantable Cardioverter Defibrillators	American Heart Association	Orlando, FL
Spring 2015	A Nationwide Study of Gender Disparities in Symptoms of Anxiety, Depression and Quality of Life in Defibrillator Recipients	Southern Nursing Research Society	Tampa, FL
Fall 2014	A Nationwide Study of Gender Disparities in Symptoms of Anxiety, Depression and Quality of Life in Defibrillator Recipients	Nursing Research Papers Day University of Kentucky College of Nursing	Lexington, KY
Fall 2012	Health Literacy Predicts Cardiovascular Disease in the Male Prison Population- oral presentation	American Heart Association Scientific Sessions	Los Angeles, CA
Spring 2012	Health Literacy Predicts Cardiovascular Disease in the Male Prison Population- oral presentation	Student Scholarship Showcase University of Kentucky College of Nursing	Lexington, KY
Spring 2012	Health Literacy Predicts Cardiovascular Disease in the Male Prison Population- poster presentation	3rd Annual Kentucky Health Literacy Summit	Lexington, KY
Fall 2010	Managing Test Anxiety	Student Success Seminar Midway College	Midway, KY
Fall 2010	Implementation of an LPN to RN Course at Midway College	Midway College	Midway, KY

Professional Memberships

Date	Organization
2014 – Present	Graduate Appalachian Research Community
2014 – Present	Kentucky Rural Health Association
2006 – Present	Sigma Theta Tau, International
2012 – Present	Preventive Cardiovascular Nurses Association
2012 – Present	American Heart Association
2012 – Present	AHA Council on Cardiovascular Nursing
2012 – Present	National League for Nursing

2012 – Present	Kentucky League for Nursing
2012 – Present	Southern Nursing Research Society
2012 – Present	American Association of Colleges of Nursing Graduate Nursing
	Nursing Academy
2003 – 2006	Preventive Cardiovascular Nurses Association
2003 – 2006	American Association of Critical Care Nurses
1996 – Present	Kentucky Nurses' Association
1996 – Present	American Nurses' Association

Academic Service
Teaching

Semester	**Course Title and Number, Credit Hours**
Spring 2017	NUR 794 Analysis, Interpretation, and Presentation of Quantitative Data University of Kentucky (Co-teacher)- 4 credit hours
Fall 2016	NUR 779 Doctoral Seminar University of Kentucky (Co-teacher) 1 credit hour
Fall 2015	Research and Evidence Based Practice University of Kentucky (TA) 3 credit hours
Spring 2015	Research and Evidence Based Practice University of Kentucky (TA) 3 credit hours
Fall 2014	Pathophysiology RN to BSN Kentucky State University 3 credit hours
Fall 2014	Community Support RN to BSN Systems Kentucky State University 4 credit hours
Fall 2014	Nursing Assessment RN to BSN Kentucky State University 3 credit hours
Fall 2014	Professional Role Transition RN to BSN Kentucky State University 3 credit hours
Spring 2014	Drug Therapy for Nursing RN to BSN Kentucky State University 2 credit hours

| Spring 2014 | Teaching and Learning in Nursing | RN to BSN |
| | Kentucky State University | 2 credit hours |

| Spring 2014 | Nursing Leadership | RN to BSN |
| | Kentucky State University | 2 credit hours |

| Spring 2014 | NUR 212 Advanced Medical Surgical Nursing | |
| | Kentucky State University | 10 credit hours |

| Spring 2014 | Nursing Clinical NUR 212 Advanced Medical Surgical Nursing Kentucky State University | |

| Fall 2013 | NUR 111 Fundamentals of Nursing | |
| | Kentucky State University | 7 credit hours |

| Fall 2013 | Nursing Clinical NUR 111 Fundamentals of Nursing Kentucky State University | |

| Fall 2013 | NUR 322 Nursing Assessment | RN to BSN |
| | Kentucky State University | 3 credit hours |

| Fall 2013 | NUR 307 Nursing Assessment | RN to BSN |
| | Kentucky State University | 2 credit hours |

| Fall 2013 | NUR 306 Pathophysiology | RN to BSN |
| | Kentucky State University | 3 credit hours |

| Spring 2013 | NUR 212 Advanced Medical Surgical Nursing | |
| | Kentucky State University | 10 credit hours |

| Spring 2013 | Nursing Clinical NUR 212 Advanced Medical Surgical Nursing Kentucky State University | |

| Fall 2012 | NUR 111 Fundamentals of Nursing | |
| | Kentucky State University | 7 credit hours |

| Fall 2012 | Nursing Clinical
NUR 111 Fundamentals of Nursing
Kentucky State University | |

Fall 2012   Nursing Clinical
              NUR 111 Fundamentals of Nursing
              Kentucky State University

Spring 2011   NUR 225 Advanced Topics in Medical Surgical Nursing
              Midway College   6 credit hours

Spring 2011   NUR 230 Nursing Transitions
              Midway College 4 credit hours

Fall 2010   NUR 225 Advanced Topics in Medical Surgical Nursing
              Midway College 6 credit hours

Fall 2010   Nursing Clinical
              NUR 225 Advanced Topics in Medical Surgical Nursing
              Midway College

Fall 2010   NUR 230 Nursing Transitions
               Midway College   4 credit hours

Spring 2010   Nursing Clinical
              NUR 120 Medical Surgical Nursing
              Midway College

Fall 2009   Nursing Clinical
              NUR 115 Foundations of Nursing
              Midway College

Academic Service
Committees

Dates	Committee Name	Role
January, 2014 – Present	Graduate Nursing Activities and Advisory Council University of Kentucky	Chair
July, 2013 – Present	Southern Nursing Research Society	Membership Liaison
April, 2013 – Present	American Association of Colleges of Nursing Graduate Nursing Student Academy	GNSA Leadership Council Liaison

January, 2013 – Present	Kentucky Health Literacy Education Committee	Member
November 2012 – May 2013	University of Kentucky College of Nursing PhD Curriculum Committee	Student Representative
October, 2012 – Present	Kentucky Nurses Association Cabinet for Governmental Affairs	Secretary
September, 2012 – May, 2013	Graduate Student Congress Professional Development Committee	Member
January, 2012 – January, 2014	Graduate Nursing Activities and Advisory Council University of Kentucky	Vice-Chair
October, 2011 – Present	Graduate Student Congress University of Kentucky	Representative
August, 2011 – January 2012	Graduate Nursing Activities and Advisory Council University of Kentucky	Member at Large
January, 2011 – June, 2011	Faculty Curriculum Committee Midway College	Member
August, 2010 – August, 2011	NLN Accreditation Survey Preparation Committee Midway College	Member
August, 2010 – June, 2011	Pharmacology Committee Midway College	Member
August, 2010 – June, 2011	LPN to RN Bridge Committee Midway College	Member
August, 2010 – June, 2011	Student Success Strategies Committee Midway College	Member
August, 2010 – June, 2011	Nursing Faculty Committee Midway College	Member

Journal Article Reviewer

Date	**Journal**
2013 – Present	European Journal of Cardiovascular Nursing
2016 – Present	Journal of Psychosomatic Research

2016 – Present	Clinical Nursing Research

Community Service

Dates	**Service**	**Role**
March 11, 2014	Operation Preparation	Mentor and adviser for 8th and 10th grade students in Franklin County who are interested in pursuing careers in health science.
November 9, 2013	66th Annual Meeting of the Kentucky State NAACP Health Screenings	Mentored students and provided blood pressure screenings and cardiovascular health wellness education to the conference attendees.
February, 2013 – Present	Eastern Regional Legislative Research Director for UniteWomen.org	Gather and maintain data on legislation at the regional level, which impacts the lives of women and minorities.
December, 2012 – Present	KY State Legislative Research Director for UniteWomen.org	Gather and maintain data on legislation at the state level, which impacts the lives of women and minorities.
October 6, 2012	65th Annual Meeting of the Kentucky State NAACP Health Screenings	Mentored students and provided blood pressure screenings and cardiovascular health wellness education to the conference attendees.
September 22, 2012	St. John A.M.E. Church Health Fair	Mentored students and provided blood pressure screenings and

		cardiovascular health wellness education to the congregation.
June, 2012 – Present	Manage an invitational community girls' fast pitch softball team.	Manage fundraising throughout the year and complete all necessary paperwork for team sanctioning, insurance and tournament enrollment
June, 2011 – Present	Course Sites Advisory Council Open source BlackBoard system for educators	Review educational material for users of the BlackBoard Platform.
April, 2000 – Present	Provide assistance to individuals who are completing applications for indigent programs through pharmaceutical companies.	Assist individuals to complete the paperwork necessary to obtain medications for free or at a reduced price through multiple pharmaceutical companies.

Continuing Education

Date	Course	Contact Hours	Presented By
May, 2014	KLN Annual Nurse Educator Conference		Kentucky League for Nursing
September, 2013	Social Epidemiology		Coursera University of Minnesota
June 26-28, 2013	Professional Grant Development Workshop		Grant Training Center University of Louisville
May 16-17, 2013	KLN Annual Conference		Kentucky League for Nursing
March 10, 2013	KNA Legislative Day		Kentucky Nurses' Association
January 1-4, 2013	Elsevier Faculty Development Conference		Elsevier Publishing
November 4-6, 2012	American Heart Association Scientific Sessions		American Heart Association
October 25, 2012	Understanding Pediatric Abusive Head Trauma	1.2 Hours	Kentucky Nurses Association
October 25, 2012	Nursing Education Would Never Be the Same: The Story of St. Joe's Nursing Program	1.2 Hours	Kentucky Nurses Association
October 25, 2012	Nursing Leadership Affecting One of Today's Most Serious Health Crises	1.2 Hours	Kentucky Nurses Association
October 25, 2012	Nursing Takes the Lead in Natural Disaster and Saves Lives	1.2 Hours	Kentucky Nurses Association

October 25, 2012	Health Care at a Turning Point. Opportunity for You and Nursing	1.2 Hours	Kentucky Nurses Association
September 21, 2012	KBN Faculty Essentials Workshop	6 Hours	Kentucky Board of Nursing
September 1, 2012	Pediatric Head Trauma	1.5 Hours	Nurse.com
March 22 and 23, 2012	3rd Annual Kentucky Health Literacy Summit	16 Hours	Kentucky Health Literacy
March 19 and 20, 2012	Motivational Interview Techniques Workshop	16 Hours	RICH Heart
March 1, 2012	Health Literacy for Public Health Professionals	1 Hour	Centers for Disease Control and Prevention
January 1, 2012	HIV/AIDS Professional Education in Kentucky…. Making It Count	3.6 Hours	Commonwealth of Kentucky Cabinet for Family Services Department for Public Health
December 26, 2011	Health Literacy 101- An Introduction to the Field	1.25 CEUs	University of Kentucky CE Central
November 13, 2011	PICC Tip Confirmation using the Sapiens Tip Confirmation System	1 CEU	Bard Access Systems

PhD Coursework

Semester	Course Number	Title
Fall 2011	NUR 779	Doctoral Seminar 1
Fall 2011	NUR 790	Knowledge Development in Nursing
Fall 2011	NUR770	Philosophical Foundations of Nursing Science
Fall 2011	NUR 771	Research Experience 1
Fall 2011	STA 580	Biostatistics 1
Spring 2012	NUR 771	Research Experience 2
Spring 2012	GRN 651	Qualitative Gerontology
Spring 2012	CPH 630	Biostatistics 2
Spring 2012	NUR779	Doctoral Seminar 2
Spring 2012	NUR 778	Seminar in Contemporary Health and Nursing Policy
Fall 2012	NUR 779	Doctoral Seminar 3
Fall 2012	NUR 792	Quantitative Methods in Nursing Research
Fall 2012	NUR 771	Research Experience 3
Spring 2013	NUR 793	Measurement of Nursing Phenomena

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Spring 2013	NUR 794	Analysis, Interpretation, and Presentation of Quantitative Data
Spring 2013	CPH 605	Epidemiology
Fall 2013	CPH 712	Advanced Epidemiology
Fall 2013	BSC 772	Race, Racism, and Health Disparities
Spring 2014	CPH 711	Chronic Disease Epidemiology
Spring 2014	NUR 767	Dissertation Residency
Spring 2014	CPH 648	Eliminating Health Disparities
Fall 2014	GS 640	Grant Writing